An investigation into the relationship between sleep problems, anxiety and challenging behaviour in children and young people with learning disabilities and/or autism spectrum disorder

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Abstract

Introduction: Children with a learning disability (LD) and/or Autism Spectrum Disorder (ASD) are known to suffer from significantly more sleep problems, anxiety and challenging behaviour (CB) than typically developing children, yet little is known about the relationships between these factors in the child LD/ASD population.

Aims and Hypotheses: The aim of the current study was to examine the relationships between sleep problems, anxiety and CB in children with LD and/or ASD. It was hypothesised that there would be differences between levels of sleep problems, anxiety and CB in children with LD alone, LD and ASD, and ASD alone. It was further hypothesised that there would be significant positive correlations between the three factors and that sleep problems and anxiety would predict a significant amount of the variance in levels of CB.

Method: Postal questionnaires were returned by parents of one hundred and sixty seven parents of children with LD and/or ASD. Questionnaires consisted of parental report measures of sleep problems, anxiety and CB, in addition to general demographic variables.

Results and Discussion: Statistical analysis revealed no difference between groups (LD, LD+ASD, ASD) in relation to sleep problems, however, some differences were found between the groups in relation to anxiety and CB. Correlational analysis

revealed significant positive associations between the three factors. A hierarchical multiple regression showed that medication, sleep problems and anxiety accounted for 42% of the variance in CB, with a large effect size. These findings suggest that the relationships between sleep, anxiety and CB found in the TD child and adult LD/ASD populations are also evident in the child LD/ASD population and that these relationships should be considered during clinical practice, particularly in the case of CB interventions where sleep problems and/or anxiety are also present.

Chapter 1: INTRODUCTION

1.1. General Introduction

Children with a learning disability (LD) and/or autism spectrum disorder (ASD) are vulnerable to more physical and psychological difficulties than typically developing (TD) children without these conditions, (Courtman and Mumby, 2008). This can lead to many challenges for the children themselves and their families. There is evidence to suggest that sleep problems, anxiety and challenging behaviour (CB) have been found to be significantly higher in the child LD and ASD populations compared to TD children (Baker et al., 2003; Emerson and Hatton, 2007; Richdale et al., 2000). There is currently some literature examining the relationships between these factors, but little has focused specifically on the child LD and ASD populations. Therefore, it is important to consider these factors and their relationships in the LD/ASD population, in order to potentially develop a theoretical understanding of the complex difficulties these children may experience, which, in turn, could help to inform intervention.

This introduction will begin with an overview of the definitions and prevalence rates of LD and ASD. This will be followed by an examination of sleep, anxiety and CB, respectively. There is currently no unifying theory which integrates all of these factors. Therefore, the possible biological/developmental, psychological and social factors which may contribute to these difficulties will be highlighted. An outline of research which describes the relationships between sleep and anxiety, sleep and CB,

and anxiety and CB will be then be presented. The introduction will end with the main aims and hypotheses of the study.

1.1.1 Identifying Previous Literature

The literature reviewed in the introduction of this study were initially identified through the Ovid Medline (R), EMB Reviews, EMBASE and PsycINFO databases from 1980 to 2009. The key terms *child, adolescent, learning disabilities, intellectual disabilities, mental retardation, autism, autism spectrum disorder, pervasive developmental disorder, sleep, sleep problems, anxiety,* and *challenging behaviour* were used in the first instance. It became apparent that studies involving anxiety or relevant emotional difficulties were often included under the '*psychopathology*' or '*psychiatric disorder*' umbrella. These terms were therefore included in the search. Similarly, '*maladaptive behaviour*' and '*problem behaviour*' were also included as search terms to identify papers that encompassed challenging behaviour. In instances where there was limited literature in the child LD/ASD population, the terms *child* and *adolescent*, and *learning disabilities* and *autism spectrum disorder* were omitted, to allow for studies about adults with LD/ASD and TD children to be identified, respectively. The searches were limited to the English language only. The reference sections of the papers identified were also studied to find any further papers which were not identified by the initial terms or which were not held electronically.

The main papers reviewed in this introduction are summarised in Tables 1.1. to 1.6. and provide information regarding the main finding, methodological strengths and weaknesses, and relevance to the current study.

Table 1.1. Summary and critique of studies examining sleep problems in child LD/ASD populations

Author	Sample	Main Finding	Strengths	Weaknesses	Why Relevant
Couturier et al. (2005).	46 children, age 5-12 years. (23 PDD; 23 TD matched controls).	Prevalence of sleep problems were significantly higher in PDD group than TD group, (78% vs. 26%, respectively).	Clear inclusion/exclusion criteria (excluded co-morbid LD from PDD group). Power calculation carried out. Well diagnosed PDD.	Small sample size therefore power was not met.	Shows significance of PDD in sleep problems without the impact of LD.
Krakowaik et al. (2008).	529 children, age 2-5 years (303 ASD; 63 Dev Delay; 163 TD).	Sleep problems found in 53% of ASD group, 46% of DD group, and 32% of TD group.	Well diagnosed sample. Clear inclusion/exclusion criteria	IQ level was not reported. No power calculation. Groups vastly different sizes.	Shows sleep problems in ASD and DD more than TD. Unclear of the impact of a co-morbid ASD and LD.
Polimeni et al. (2005).	171 children, age 2-17 years (66 TD; 53 Autism; 52 Asperger's Syndrome).	Sleep problems found in 73% of Autism and Asperger's group. This was significantly more that the 50% shown in TD children. Autism group showed most improvement in behaviour treatment for sleep problems.	Included IQ. Adequate sample size.	No inclusion/exclusion criteria. No power calculation. Reported treatment outcomes, but limited information about the specifics of treatment programmes.	Shows sleep problems are significantly higher in Autism and Asperger's compared to TD children. No difference found between Autism and Asperger's. Autism group responded well to behavioural intervention.
Quine, (2001).	758, 4-12 years, (182 Special School; 576 mainstream school).	Children attending special school showed significantly more sleep problems than children attending mainstream school. Maternal stress was related to various sleep problems in both groups.	Large sample size. Used comparison group (i.e. mainstream school).	No inclusion/exclusion criteria noted. Little description of sleep scale used. No specific description of LD. No note of co-morbid condition (e.g. ASD).	Identifies sleep problems in a non-clinical group of children with LD. Author discusses impact of maternal stress on sleep problems.
Schreck and Mulick, (2000).	171, age 5-12 years. (22 LD; 55 ASD; 49 Special Education; 45 Control).	No difference in the number of hours slept between the groups, but the ASD group showed poorer quality of sleep and poorer sleep behaviour. Parental perception of sleep problems significantly higher in ASD group.	Adequate sample size overall. Used control.	No IQ noted. No power calculation. No indication of co-morbid ASD in LD group, or co-morbid LD in ASD group.	Shows differences in quality of sleep and sleep behaviour between LD and ASD, but no indication of the impact of co-morbid ASD and LD.
Williams et al. (2004).	210, age 2-16 years. (127 LD+ASD; 83 ASD alone).	High prevalence of sleep problems in both groups. Some specific differences in sleep problems between groups.	Well diagnosed LD. Adequate sample size.	No description of ASD diagnosis. No power calculation. Little discussion of main findings, and explanations for this.	Some differences in sleep problems between groups suggests high impact of LD+ASD, but this was not the case for all sleep problems studied.

Table 1.2. Summary and critique of studies examining anxiety (psychopathology / psychiatric disorder) in child LD/ASD populations

Author	Sample	Main Finding	Strengths	Weaknesses	Why Relevant
Brereton et al. (2006).	917 children , age 4-18 years (367 ASD; 550 LD).	The ASD group showed significantly higher levels of psychopathology overall, including anxiety subscale of the Developmental Behaviour Checklist (DBC).	Large sample size. ASD and LD well diagnosed.	Unclear of the overlap between ASD and LD in the ASD group. Not all subscales of the DBC analysed involving IQ. No inclusion/exclusion criteria stated. No power calculation.	Shows increased psychopathology in ASD group compared to LD group. Suggests some areas of psychopathology are most severe when ASD is combined with low IQ, but does not examine this specifically in anxiety subscale.
Einfeld and Tonge, (1996a + b).	454 children, age 4-18 years with LD.	40.7% of the sample showed severe emotional and behavioural disturbance, including anxiety. This was significantly higher in the mild to moderate IQ range than the severe to profound range.	Large sample size. Majority had IQ measures. Power calculation carried out and Bonferroni corrections used for multiple comparisons.	Inclusion and exclusion criteria not clearly stated. Unclear how many of the sample had co-morbid ASD.	Shows high level of psychopathology, including anxiety, in children with LD. Unclear of how co-morbid ASD may impact on this.
Muris et al. (1998).	44 children, age 2-18 years, with PDD.	81.4% of the sample met full criteria for at least one anxiety disorder.	Used questionnaire method but in interview setting. Well diagnosed PDD.	No inclusion/exclusion criteria. No power calculation. No control group.	Shows high levels of anxiety in children with PDD. Authors highlight the importance of examining anxiety specifically, and not viewing it as a core part of ASD.
Simonoff et al. (2008).	112 children, age 10-14 years, with ASD.	70% of the children met criteria for at least one anxiety disorder, 41% had two or more. Also showed high rates of Attention Deficit Hyperactivity Disorder in the sample.	Well diagnosed sample. Standardised interview used.	No power calculation. Narrow age range used.	High levels of anxiety disorder identified in children with ASD.

Table 1.3. Summary and critique of studies examining challenging behaviour in child LD/ASD populations

Author	Sample	Main Finding	Strengths	Weaknesses	Why Relevant
Adams and Allen, (2001).	56 children, 5-18 years with LD.	Aggression was a daily event for 60% of the sample. Carers were injured as a result of CB in over two thirds of cases.	Used questionnaire method but conducted in an interview setting.	Relatively small sample size. No power calculation. Inclusion/exclusion not explicitly stated.	Shows high levels of CB in a clinical sample. Highlights lack of understanding about CB in individuals who work with children with LD.
Baker et al. (2003).	205 children, age 3 years. (82 developmental delay; 123 no delay).	Children with delay showed significantly more behaviour problems than those without delay. Parent stressors in delayed group related to behaviour problem rather than delay specifically. Behaviour was stable over one year.	Clear inclusion/exclusion criteria (ASD excluded). Large sample size.	No power calculation. Delayed group not further divided into mild/moderate/severe.	Shows CB evident from a young age, and parental stress associated with problem behaviour. Authors suggest parent stress impacts on parenting skills, and a mutually escalating effect of parent stress and child's CB.
Emerson et al. (2001).	Total population study.	CB shown by 10-15% of people with LD, including aggression, and self injury. Most people show multiple forms of CB. High levels of CB associated with poor adaptive and language skills.	Wide range of sample as a total population study. Examined CB over time.	Unclear of actual sample size or how studies are reviewed.	Shows levels of CB from a total population study in LD. Unclear of impact of ASD on CB.
Lowe et al. (2007).	Total population sample of 901 individuals with LD. Included 196 children, almost half of whom had co-morbid ASD.	CB evident in 10% of the LD population overall. Children specifically showed high levels of moderate to serious CB (17%-42%).	Combined questionnaire and interview methods. Conducted inter-respondent reliability measures. Wide age range allows for seeing CB across the lifespan.	No inclusion/exclusion criteria noted. No power calculation.	Shows high prevalence of CB in LD. High percentage of co-morbid ASD in child sample suggests high prevalence of CB in children with LD+ASD, but study does not analyse these groups separately.
McClintock et al. (2003).	Meta-analysis of 22 studies, including 6 studies involving children.	Risk markers for CB in individuals with CB include male gender, severe LD, poor communication, and diagnosis of ASD.	Rigorous identification of studies. 64 were excluded before analysis due to poor methodology etc.	Highlights possible interaction of risk factors, therefore cannot identify the extent to which each one is associated with CB.	Highlights increased likelihood of CB in individuals with LD if there is co-morbid ASD. Identifies other pertinent factors in CB, such as communication.

Table 1.4. Summary and critique of studies examining the relationship between sleep and anxiety (psychopathology/psychiatric disorder)

Author	Sample	Main Finding	Strengths	Weaknesses	Why Relevant
Alfano et al. (2006).	106 TD children, 6-17 years. (3 Groups: Anxiety; Sleep Problems; Healthy Controls).	Sleep problems were significantly higher in the sleep problem and anxiety group than in controls. 83% of anxiety group reported intermittent sleep problems, and over half reported regular sleep problems.	Used a control group. Well diagnosed anxiety participants.	No power calculation. Retrospective chart review, not prospective data. Small sample size (between groups). No specific sleep assessment, but used the sleep questions from a behavioural questionnaire.	Shows association between sleep and anxiety in TD children. Examined anxiety specifically.
Alfano et al. (2007).	128 TD children with anxiety disorders, 6-17 years.	Sleep problems found to be prominent, 88% experienced one sleep problem, 55% experienced 3 or more sleep problems.	Adequate sample size. Well diagnosed anxiety disorders.	No specific sleep assessment, but used sleep questions from other questionnaires. No power calculation.	Shows association between sleep and anxiety in TD children. Examined anxiety specifically.
Allik et al. (2006).	64, 5-12 years. (32 HFA/AS; 32 healthy controls).	HFA/AS group showed significantly more sleep problems and insomnia than control group. Positive correlation between emotional subscale of SDQ and insomnia.	Well diagnosed HFA/AS group. Used control group.	Small sample size. No power calculation.	Touches on the relationship between emotional state and sleep problems in an ASD population.
Chroney et al. (2007).	N/A (Review Paper).	Overall, literature reports positive correlations between sleep and psychopathology in TD children.	Discusses sleep problems in relation to different anxiety and mood disorders.	Solely focuses on the TD population. No discussion of LD/ASD.	Shows relationship between sleep and psychopathology in TD population. Authors note that this is an association, and does not suggest direction or causation. Call for more research in this area.
El-Sheikh et al. (2007).	166 TD children, mean age 8 years.	Emotionally secure children showed more consolidated sleep than emotionally insecure children. Poor quality of sleep had a negative impact on child's behaviour, emotion, and academic performance.	Used actigraphy as an objective sleep measurement. Results related to a theoretical model.	No power calculation.	Shows the impact of poor sleep on emotion in TD children.

Table 1.5. Summary and critique of studies involving sleep and challenging behaviour

Author	Sample	Main Finding	Strengths	Weaknesses	Why Relevant
Brylewski & Wiggs, (1999).	205 adults with LD.	Divided sample into poor sleepers and good sleepers. Poor sleepers showed significantly more CB than good sleepers.	Large sample size. Used self-report when possible.	No power calculation. No IQ stated. No note of now many participants had co-morbid ASD, or if this was an exclusion criteria. Little description of sleep measure.	Shows an association between sleep and CB in adults with LD. Mirrors findings in children.
DeVincent et al. (2007).	609 children, 3-5 years. (112 PDD; 497 healthy controls).	PDD group showed significantly more sleep problems than controls. Children with sleep problems (in either group) showed significantly more behaviour problems.	Large sample size. Used control group. Reports IQ scores. Majority of PDD group well diagnosed.	No power calculation. Statistics conducted only allowed for an association to be found, therefore limited information about the relationship between sleep and behaviour.	Shows an association between sleep and behaviour in a PDD children, but limited information about this relationship.
Didden et al. (2002).	286 children, 1-19 years, mixed LD plus ASD.	Children with sleep problems showed more CB than children without sleep problems.	Noted co-morbid LD and ASD. Large sample size. Reported IQ scores. Used non-parametric statistics when scores were not normally distributed.	Did not investigate the impact of co-morbid ASD. No power calculation.	Shows association between sleep and CB in LD/ASD population. Authors suggest the involvement of psychological factors such as anxiety, but do not explore this.
Richdale et al. (2000).	77 children, 2-19 years. (52 LD/ASD; 25 TD controls).	Presence of sleep problems was significantly associated with intensity and frequency of parent hassles and presence of CB.	Used control group. Examined impact of IQ.	No power calculation. Only 7 co-morbid ASD, therefore not enough for separate analysis. Inclusion/exclusion criteria not clearly stated.	Shows an association between sleep and CB in LD/ASD population. Sleep and CB both associated with parental stress.
Stein et al. (2001).	472 TD children, 4-12 years.	Sleep problems are positively correlated with internalising and externalising behaviours.	Large sample size. Comprehensive statistics	No power calculation. No inclusion/exclusion criteria stated. Little description of sleep measure.	Shows an association between sleep and behaviour in TD children.
Wiggs & Stores, (1996).	209 LD/ASD children, 5-16 years.	Children with sleep problems showed a greater number, and intensity of, CBs than children without sleep problems.	Large sample size. Noted the proportion of co-morbid LD and ASD.	No power calculation. Did not explore any differences between LD and ASD. Statistics conducted only allowed for an association to be found, therefore limited information about the relationship between sleep and behaviour.	Shows an association between sleep and CB in children with LD/ASD, but limited information about this relationship.

Table 1.6. Summary and critique of studies examining the relationship between anxiety and challenging behaviour

Author	Sample	Main Finding	Strengths	Weaknesses	Why Relevant
Allen & Davis, (2007).	N/A Review Paper.	Overall, the literature shows positive correlations between psychiatric illness and CB. Authors suggest that it is unlikely that a simple relationship exists between psychiatric illness and CB.	Focuses on an LD population	Does not separate LD and ASD. Examines psychopathology in general, rather than specific anxiety and mood disorders.	Authors highlight that whilst most current research shows an association between psychiatric illness and CB, further research must be conducted to understand more about the relationship between these variables.
Bradely et al. (2004).	24, age 14-20 years. (12 ASD plus LD; 12 matched LD alone).	Relationship between emotional and behavioural disturbance found in both groups, but was significantly higher in the LD plus ASD group.	Well diagnosed participants. Well matched groups. Explored impact of co-morbid LD and ASD diagnosis.	No power calculation. Small sample size. Statistics limited to association between variables due to small sample size. Explores emotion in general.	Shows an association between emotion and behaviour in LD/ASD, but not anxiety specifically.
Hemmings et al. (2006).	214 adults with LD.	Self injury and aggression were associated with affective symptoms. Screaming and destructive behaviour associated with social impairments evident in participants with co-morbid ASD.	IQ recorded where available. Large sample size.	No power calculation. No information regarding co-morbid medical conditions, medication etc. Inclusion/exclusion criteria not clearly stated.	Shows an association between psychiatric symptoms and specific CBs. Discusses behaviour equivalents of psychiatric disorder, but notes that these relationships are unlikely to be straight forward.
Holden & Gitlesen, (2008).	146 adults with LD.	Relationship found between psychopathology and CB. However, they did not find that the function of a CB could be predicted by a mental health disorder.	Large sample size. IQ noted (but not included in the analysis).	No power calculation. Inclusion/exclusion criteria not stated. Authors suggest that measures should be more robust. Unclear which assessment was used to measure CB.	Shows an association between psychopathology and CB. Begins to examine this relationship further by looking at factors predictive of the function of a CB.
Myrbakk & von Tetzchner, (2008).	181, 14-72 years with LD.	Divided sample into problem behaviour and no problem behaviour. Problem behaviour group showed significantly more psychiatric symptoms and disorders.	Multiple psychiatric measures used. IQ scores reported.	No power calculation. Unclear proportion of co-morbid LD plus ASD. Statistics only allowed for an association to be found, therefore limited information on the relationship between sleep and psychiatric disorder. Multiple correlations carried out with no adjustment of alpha level.	Shows an association between CB and psychiatric disorder a total population study of individuals with LD.

1.2. Introduction to LD and ASD

The term 'learning disability' (LD) is often used synonymously in the literature with intellectual disability or mental retardation. Throughout this study, the term 'learning disability' will be used as this is the preferred terminology used by the British Psychological Society (2000).

The term 'Autism Spectrum Disorder' is often used synonymously in the literature with 'Pervasive Developmental Disorder'. Throughout this study, the term Autism Spectrum Disorder' (ASD) will be used as this is the preferred terminology used in the SIGN Guidelines (Scottish Intercollegiate Guidelines Network, Guideline 98, 2007).

This section will go on to give the definitions and prevalence rates of LD and ASD in the child population.

1.2.1. Definition of LD

There are currently different classification systems which can be used to define a LD. The Diagnostic and Statistical Manual of Mental Disorders (4th Edition; American Psychiatric Association, 2000 [DSM-IV]) states three main criteria, all of which must be met, namely: a significant cognitive impairment (IQ below 70); deficits in at least two areas of adaptive functioning; and onset before 18 years of age. The British Psychological Society (2000) states the same three components as the DSM-IV. The International Classification of Diseases (10th Edition; World Health Organisation,

1992 [ICD-10]) gives a very similar, but slightly broader definition. It describes incomplete or arrested development of the mind, which is evident in deficits in skills and abilities. Rather than specifying an age, it states that this must happen in the developmental period. This definition also suggests that improvement may be seen over time, if the appropriate support is given.

Despite some criticisms of the definition of LD, for example that the cut-off scores are essentially arbitrary and do not account for increases in IQ over time (Flynn, 1984; Kanaya et al., 2003), there is a general consensus about the three defining factors.

Irrespective of the classification system used, individuals with a LD are likely to have difficulties in a range of areas including verbal communication, understanding, planning, sequencing, abstract thinking and reasoning (Siegel, 1989). Many individuals with LD have limited communication skills, and experience problems with day-to-day living skills and social interactions and situations (Courtman and Mumby, 2008). A learning disability is also often accompanied by various co-morbid sensory and medical conditions such as visual impairment, gene and chromosome abnormalities, cerebral palsy, epilepsy and mobility problems (Courtman and Mumby, 2008; Volkmar et al., 2004). In turn, health disorders have been found to impact on mental health (Kwok and Cheung, 2007). Whilst there is no identifiable cause for over half of LDs, the most common known causes are Down Syndrome (DS) and Foetal Alcohol Syndrome (Minns, 1997). There are varying degrees of severity of LD which are commonly classified as mild (IQ 50-55 up to

70); moderate (IQ 35-40 up to 50-55); severe (IQ 20-25 up to 30-35) and profound (IQ below 20-25), as suggested by ICD-10. This leads to a diverse range of presentations within the broader LD definition.

1.2.3. Prevalence of LD in Children

The 'Changing Childhoods?' report (Scottish Executive, 2006) is a follow up study of the 'Same As You?' document, focusing on children with LD/ASD. This report states that in 2004, there were 28,300 children living in Scotland with LD. Many of these children will live at home with their families, be supported in mainstream education and have limited contact with health services. For others, however, ongoing support from various health and social services will be required to support the children, their families and the staff providing input (Scottish Executive, 2006).

1.2.4. Definition of ASD

Autism Spectrum Disorders are termed 'Pervasive Developmental Disorders' in the DSM-IV and ICD-10. Both diagnostic systems suggest a similar triad of impairments must be evident in order to gain a diagnosis. This triad consists of deficits in social interaction, language and communication, and thought and behaviour. The ICD-10 and DSM-IV vary slightly in terminology of the specific conditions under the PDD umbrella. For example, 'classic' autism is known as 'Childhood Autism' in ICD-10, but 'Autistic Disorder' in DSM-IV. Similarly, ICD-10 refers to 'Atypical Autism' as a separate condition, but this is included in 'Pervasive Developmental Disorders-Not Otherwise Specified' in DSM-IV. Both classification systems identify 'Asperger's Syndrome' (AS) and 'Rett's Syndrome'.

Both classifications stipulate that for a diagnosis of AS the triad of impairments must be evident, but this is not accompanied by clinically significant delay in language development, or a clinically significant delay in cognitive development. Both classifications also state that Rett's Syndrome is characterised by normal early development followed by loss of speech, mobility and skills. The development of social and play skills are also diminished and cognitive skills severely impaired, (DSM-IV; ICD-10).

Although all children with ASD will have the triad of impairments, this may present differently in each child, leading to a diverse range of presentations. Impairments in social interactions include delayed or atypical social development, particularly in interpersonal development. This can lead to an 'aloof' child, who appears to be disinterested in others, shows limited facial expressions and eye contact, does not enjoy physical contact and does not show empathy towards others (Frith, 2003).

Impairments in language and communication are evident in children with ASD who do, and do not, have language delay (Joseph et al., 2002). This is evident in deficits in verbal and non-verbal communication and a particular difficulty with pragmatic features of language (Baron-Cohen, 2008). Some children with ASD will have no or limited verbal skills. For those who do have verbal skills, atypical use of language is evident in repetition of words or phrases, imitation of accents or intonation of others, or the inappropriate use of language for the situation. For children with more advanced language skills, their speech tends to be repetitive rather than conversational, with a focus on their own interests (Wing, 1996). Difficulties in

understanding and responding to non-verbal communication such as facial expressions are also apparent (Wang, 2004).

Impairments in thought and behaviour are shown by a deficit in social imagination and rigidity of thought and behaviour (Frith, 2003). This is often accompanied by some form of ritualistic behaviour and a need for routine and structure (Baron-Cohen, 2008). A lack of imagination can often lead to difficulties in sequencing of events, planning and the foresight to see the consequences of actions (Wing, 1996). If a child does not enjoy activities that involve creative and flexible thinking or imagination and has little interest in others, then they may engage in repetitive idiosyncratic behaviours which give them pleasure (Baron-Cohen, 2008). This could be seen in sensory activities (such as smelling or touching surfaces), repetitive movements, or elaborate rituals or routines.

1.2.5. Comorbid LD and ASD

ASDs are evident across a range of IQ levels, which means that a child can be diagnosed with both ASD and LD. Recent figures suggest that up to 75% of children with ASD also have a LD, which indicates a very high prevalence of children with both LD and ASD (Croen et al., 2002). This could lead to further diverse and complex presentations of children with ASD and LD.

1.2.6. Prevalence of ASD in Children

Volkmar et al. (2004) report that although it appears that the prevalence of ASD has increased over the past 30 years, this is most likely to be due to increased awareness

of the disorder, leading to an increase in the number of diagnoses made. Alongside this, they highlight the difficulty in estimating prevalence in ASD due to differing diagnostic criteria and inclusion/exclusion criteria in studies. However, a recent study by Baird et al. (2006) suggested a prevalence rate of 116.1 per 10,000 in primary school age children. ASD is also more prevalent in males than females, at a ratio of approximately 4:1 (Fombonne, 1999). However, this is likely to vary across specific conditions, for example, Rett's Syndrome is only evident in females. As with LD, many of these children will be supported by their parents within the family home, attend mainstream education and have limited contact with services (Scottish Executive, 2006). For others, however, ongoing support from health and social services will be required for individuals and their families.

1.2.7. Psychological Theories of ASD

Unlike LD, there are various psychological theories which are thought to explain aspects of ASD. There have been three key theories proposed over the past decade. Firstly, the Theory of Mind Hypothesis (Baron-Cohen 1995) developed from the social cognitive domain, postulates that the social dysfunction observed in ASD is a disruption in the theory of mind process. This is the ability and capacity to understand others' and one's own mind. Secondly, the Weak Central Coherence Hypothesis (Happe and Frith, 1996) emerged from the general learning domain. It suggests that individuals with ASD process stimuli in a fragmented fashion, focusing on detail and not on the meaningful whole. Thirdly, the Executive Dysfunction Hypothesis (Pennington & Ozonoff, 1996), also developed from the general learning domain, focuses on self organisation of elements, which guides attention, abstract

thinking, the generation of goals and inhibition of irrelevant responses. Poor self regulation would, therefore, result in difficulties with change, forward planning and problem solving. Whilst these models have been tested throughout the literature and each has found some validity, criticism remains around lack of explanatory power (Volkmar et al., 2004).

1.2.8. Summary

In summary, children with LD and ASD encompass an important proportion of the child population. The diagnostic criteria are broad, allowing for a wide range of presentations within the child LD and ASD population. Additionally, LD and ASD can occur alone, or co-exist. The next section will go on to describe sleep problems in children with LD and/or ASD.

1.3. Sleep Problems

1.3.1. Introduction to Sleep Problems

It is thought that the multiple functions of sleep include physical and psychological rehabilitation, energy conservation, brain growth, and consolidation of memories (Stores, 2001a). It is unsurprising, therefore, that there is a wealth of literature showing the negative impact of sleep deprivation. Impairments in memory, learning, vigilance, creative thought, verbal abilities and attention are only some of the ways in which lack of sleep is thought to affect children (Fallone et al., 2005; Gozal, 1998). These may impact on academic performance and would be particularly detrimental to children who already had difficulties in these areas (Blunden and Chervin, 2008). It

is also widely acknowledged that caring for a child with LD and/or ASD is generally more stressful than caring for a TD child (Eisenhower et al., 2005; Hoare et al., 1998), and this can be exacerbated by the child's sleep problems (e.g. Hoffman et al., 2008).

This section will describe the sleep problems experienced by children with LD and/or ASD. It will begin with a definition of sleep problems and sleep architecture. It will go on to describe sleep problems in TD children and then in children with LD and ASD. Relevant developmental/biological, psychological and social factors will then be discussed.

1.3.2. Definition of Sleep Disorders and Problems

It is important to distinguish between sleep disorders and sleep problems. Whilst mainly of adult orientation, there are over 80 different sleep disorders identified in the International Classification of Sleep Disorders-Revised, (American Sleep Disorders Association, 1997). There are three primary classifications of sleep disorders: dysomnias are sleep disorders which cause difficulty getting to sleep, staying asleep, or excessive daytime sleepiness; parasomnias are sleep disorders which disrupt the sleep process once an individual is asleep; and sleep disorders which are associated with neurology or other medical disorders.

Sleep 'problems' are often defined as;

"sleep behaviour that is disturbing in some way to the child, the child's family, or both; and is distinct from a 'sleep disorder' which implies an underlying abnormal function" (Richdale, 1999, p.60).

In a similar vein to the primary sleep disorder classification, Stores and Wiggs (2001) suggest that there are three primary categories of sleep problems: difficulty getting to sleep or staying asleep; sleeping too much; and disturbed episodes that interfere with sleep. Within these broader categories common sleep problems include refusal to go to bed, distress around going to bed, refusal to sleep in own bed, co-sleeping, delayed sleep onset, frequent waking during the night, nightmares, sleep walking, snoring, early morning waking and excessive daytime sleepiness (Espie, 2000).

1.3.3. Sleep Architecture and Normal Sleep Development

The circadian clock (the suprachiasmatic nucleus of the hypothalamus) regulates endogenous circadian rhythms which are aligned with social and environmental cues (Brandon and Zee, 2006). Essentially, this clock programs humans to be awake during the day and to sleep at night. As humans move from awake to asleep, there is a progressive slowing of electrical activity in the brain (Stores, 2001a), which can be monitored by an electroencephalogram (EEG). There are four stages of non-rapid eye movement (NREM) sleep, with EEG activity slowing as the stage number increases. Rapid eye movement sleep is a separate stage of sleep, characterised by high rates of brain activity (Stores, 2001a). There is a high frequency of REM sleep in early life, which decreases with age (Brandon and Zee, 2006).

New-born babies and infants do not distinguish between night and day. However, this is established quite quickly as sleep develops to be mainly at night and naps are shortened during the day (Richdale and Prior, 1995). Many young children will be

sleeping through the night by one year of age, daytime naps are extinguished by around age 3-5 years, and an adult pattern of sleep will gradually develop and be established by adolescence (Robinson and Waters, 2008). However, difficulties with settling, night time waking and early morning waking are common in up to 25% of typically developing school age children, but will generally improve with age (Scher et al., 1995).

1.3.4. Sleep Problems in Children with LD and ASD

1.3.4.1. Sleep Problems in Children with LD

There is general consensus in the literature that there is a high prevalence of sleep problems in children with LD. Studies involving prevalence rates have estimated that sleep problems in children with LD range from 34% to 86% (Bartlett, 1985; Johnson 1996, Wiggs and Stores, 1996). Significantly more sleep problems have been found in the child LD population when compared to TD children (Richdale et al., 2000). These sleep problems include settling problems, night waking, daytime sleepiness, head banging in bed and night wetting (Quine, 2001). Furthermore, these types of sleep problems have been found in adults with LD, suggesting that difficulties seen in childhood are likely to continue to some degree into adulthood (Brylewski and Wiggs, 1998). The wide range of prevalence rates of sleep problems in children with LD could be due to differences in methodology, sample size or identification (community or clinical) and method of sleep measurement.

1.3.4.2. Sleep Problems in Children with ASD

There is also a wealth of literature regarding sleep problems in children with ASD. Studies examining prevalence rates have estimated that sleep problems in children with ASD range from 53% to 78% (Couturier et al., 2005; Paavonen et al., 2008; Polimeni et al., 2005). Significantly more sleep problems have been identified in children with ASD when compared to TD children (Allik et al., 2006; Honomichl et al., 2002; Patzold et al., 1998; Richdale and Prior, 1995). In contrast to these findings, Hering et al. (1999) did not report significant differences between the sleep patterns of children with ASD compared to TD children. However, these authors note that a very small sample size and limited ASD diagnosis information may have contributed to these results. Similar difficulties are likely to have contributed to the varying prevalence rates noted in the previous studies.

1.3.4.3. Sleep Problems in Children with LD Compared to ASD

Various studies have compared LD and ASD groups and have revealed mixed findings. Some studies suggest that children with ASD may experience significantly more sleep problems than children with LD (e.g. Krakowiak et al., 2008). However, Schreck and Mulick (2000) reported no difference between the number of hours slept between children with LD and ASD, but that children with ASD had poorer quality of sleep and poorer sleep behaviour. When examining children with ASD alone compared to children with LD plus ASD, Williams et al. (2004) found a high prevalence rate of sleep problems in both groups, and some specific sleep problems (e.g. night waking) were significantly more common in the LD plus ASD group. Again, there are various methodological difficulties in these studies (e.g. small sample sizes, inclusion/exclusion criteria not reported, lack of description of sample

or findings) which may account for the difference in findings between studies (e.g. Couturier et al., 2005; Polimeni et al., 2005). Additionally, there is limited research on the impact of co-morbid LD and ASD when compared to LD alone or ASD alone.

1.3.5. Aetiology of Sleep Problems in Children with LD and ASD

The evidence presented above indicates that sleep problems are significantly more prevalent in the LD/ASD population compared to the TD population. Whilst there is no single definitive theory to explain why this is, there are several developmental/biological, psychological and social factors which suggest why this may be the case.

1.3.5.1. Developmental/Biological Factors

Syndromes and Medical Conditions

There is some evidence to suggest that there is a higher prevalence of sleep disorders and problems in some syndromes and medical conditions associated with LD. Children with Down Syndrome (DS) are vulnerable to upper airway obstructions, unusual tongue position and enlarged tonsils and adenoids, which can lead to breathing difficulties and disruption of REM sleep, thereby increasing the likelihood of sleep problems, (Levanon et al., 1999; Miano et al., 2008; Stores, 2001b). Many studies have found sleep problems in children with DS to be more common than in TD children (e.g. Fields et al., 1995). Stores et al. (1996) examined sleep problems in children with DS, non specific LD and TD children. The authors found that both the DS and LD groups had significantly more sleep problems than the TD group.

Studies involving children with Prader-Willi Syndrome (PWS) report excessive daytime sleepiness (Clift et al., 1994; Richdale et al., 1999). PWS is a rare genetic disorder in which genes are missing or unexpressed on chromosome 15. This syndrome is often accompanied by LD, obesity and CB, (DSM-IV). Interestingly, in a study by Cotton and Richdale (2006), children with ASD, DS, PWS and LD were all found to have up to four times more sleep problems than TD children, and these were most common in the ASD group. Epilepsy is one of the most common medical conditions associated with LD and sleep problems, and has been found to impact negatively on sleep of TD children (e.g. Cortesi et al., 1999; Stores et al., 1998) and individuals with LD (Giannotti et al., 2008).

Circadian Rhythm/Melatonin Production

It has been proposed that individuals with LD may have circadian rhythm dysfunction or disorders, and abnormalities in melatonin production, which can impact on normal sleep patterns. Individuals with LD and/or ASD have been found to have increased stage one sleep and less REM sleep (Brandon and Zee, 2006; Levanon et al., 1999). Melatonin is an endogenous hormone, produced by the pineal gland during darkness, and appears to be involved in the phase setting of the circadian clock (Wehr et al., 2001). Melatonin should be produced during daylight and activated at night, but this cycle has been found to be disrupted in individuals with LD/ASD, leading to a deficiency in melatonin production (Hare et al., 2006; Sajith and Clark, 2007).

Intelligence Quotient (IQ)

Sleep problems occur at all levels of IQ within LD and ASD, but there is some debate in the literature as to how IQ impacts on the severity of the sleep problem, if at all. Richdale and Prior (1995) found more sleep problems in children with ASD with a higher IQ when compared to children with ASD with a lower IQ. Richdale (1999) reports that some studies suggest that sleep problems increase as IQ decreases. Other studies have found no impact of IQ level on sleep problems (e.g. Patzold et al., 1998; Williams et al., 2004).

Age

There has been mixed evidence in the literature to suggest that sleep problems in children with LD and/or ASD might improve with age, as is seen in TD children. For example, in a study of children (aged 3-19 years) with ASD, Richdale and Prior (1995) found that sleep problems did improve with age, with most severe problems seen under 8 years of age. However, Quine (2001) found that most sleep problems in children attending mainstream school improved with age, but only night waking and sleeping in the parental bed improved with age in children attending special school. Therefore, it is unclear if sleep problems in children with LD and/or ASD will improve with age, as is expected in TD children.

Sensory Problems

As noted previously, children with LD are particularly prone to sensory impairments and these, in turn, have been associated with sleep problems. Hodapp (1998) reports that 17% of children with LD have hearing impairments and 30% have visual impairments. It seems reasonable that, given the impact of the environment, daylight

and darkness on the circadian clock, individuals with severe visual impairments may have difficulties sleeping. Children with LD and a visual impairment have been found to have significantly more sleep problems than healthy controls (e.g. Carvil, 2001), and it has been reported that a visual impairment impacts negatively on sleep, outwith the possible influence of the LD.

1.3.5.2. Psychological Factors

Parental Factors

It has been noted that parents of children with LD/ASD sometimes believe that sleep problems are inherent in the LD/ASD population and subsequently do not believe that they may be changeable (Honomichl et al., 2002; Polimeni et al., 2005; Robinson and Richdale, 2003). Additionally, it has been shown that sleep problems in children with LD/ASD result in greater levels of parental stress (e.g. Hoffman et al., 2008). Parental stress has also been shown to impact on quality of care, possibly resulting in ineffective and inconsistent parenting strategies being implemented around the child's sleep problems (Quine, 2001).

Routines and Rituals

One of the core features of ASD is the need for routine and consistency. It has been speculated that some children with ASD may have established a very poor bedtime routine. As children with ASD have a strong need for routine and become distressed when routines are changed, parents may find it particularly difficult to set new boundaries and structure around bedtime behaviour (Patzold et al., 1998).

1.3.5.3. Social Factors

Social/Communication Difficulties

Children with LD/ASD are likely to be affected by social and communication difficulties, which can potentially impact on the sleep/wake cycle. Humans are thought to use social cues (such as the family getting ready for bed) as well as environmental cues (such as light and dark) to help maintain their circadian rhythm (Brandon and Zee, 2006). If a child is unable to identify social and environmental cues, this could lead to problems in the sleep-wake cycle (Richdale, 1999).

1.3.6. Summary

In summary, the evidence suggests that whilst TD children (particularly those with anxiety disorders) show sleep problems, the prevalence of sleep problems is significantly higher in children with LD and/or ASD compared to TD children. However, there has been some conflicting evidence in the literature as to whether the prevalence of sleep problems is different between LD and ASD groups. There are several developmental/biological, psychological and social factors which may contribute to the high prevalence of sleep problems in children with LD and/or ASD. The next section will go on to describe anxiety in children with LD and/or ASD.

1.4. Anxiety

1.4.1. Introduction to Anxiety

It is only in recent times that the emotional state of individuals with LD/ASD has been recognised (Arthur, 2003). There has been far less research carried out in the field of anxiety in LD/ASD, compared to other psychological difficulties such as depression. Within the ASD field, there has been some debate in the literature as to whether anxiety should be viewed as a core feature of ASD and would therefore not warrant a separate diagnosis (e.g. Matson and Nebel-Schwalm, 2007). However, these authors note that ASD symptoms should be fairly stable over time, therefore fluctuation in symptoms may be indicative of psychopathology and families may access clinical services if this occurs. As with all mental health disorders, anxiety has a negative impact on the child and their family. This could result in parents feeling stressed and helpless (Faust and Scior, 2007) and children feeling confused and vulnerable (Berg et al., 2002).

This section will give a definition of anxiety and outline some of the difficulties associated with the assessment and diagnosis of anxiety in the LD/ASD population. Studies examining anxiety in LD/ASD populations will then be described. Relevant developmental/biological, psychological and social factors will then be highlighted.

1.4.2. Definition of Anxiety

Anxiety can be a productive and helpful experience if it occurs at appropriate times and at optimal levels. However, an anxiety disorder is evident when levels of threat

and danger are misinterpreted, or the intensity and duration of the anxiety experienced is disproportionate to the level of threat (Cooray and Bakala, 2005). The DSM-IV and ICD-10 both classify the anxiety disorders in sub-types such as panic disorder (with and without agoraphobia), specific phobia, social phobia, obsessive compulsive disorder, post traumatic stress disorder, and generalised anxiety disorder. Generally, all encompass cognitive symptoms such as worrying thoughts, physiological symptoms such as increased heart rate, and specific behaviours such as compensatory strategies.

1.4.3. Assessment and Diagnosis of Anxiety in Children with LD and/or ASD

There is no gold standard for assessing psychopathology in individuals with LD and/or ASD, making assessment and diagnosis problematic (McBrien, 2003). Cooray and Bakala (2005) reported that current classification systems are based on studies which exclude LD and may therefore be of limited use for this population. Anxiety rating scales have also been developed mainly for the TD population, and there are limited measures available for use in the child LD/ASD population specifically. Lainhart (1999) highlights the difficulty of acquiescence in individuals with LD, which could lead to unreliable responding. Matson et al. (1997) note that the verbal expression of anxiety requires a certain level of cognitive and verbal skills. Therefore, in the LD/ASD population, it may be more likely to be expressed through behaviour and must be observed by a second party. However, Glenn et al. (2003) conducted a study examining cognitions related to anxiety in adults with mild to moderate LD and reported that after helping individuals with LD to access their

thoughts, maladaptive cognitions accounted for 74% of the variance of anxiety in their sample.

The literature on anxiety in children with LD/ASD commonly refers to the problem of diagnostic overshadowing. This occurs when behaviours that are actually indicative of psychopathology are assumed to be a part of the LD or ASD and are therefore assumed not to require clinical attention. Matson and Nebel-Schwalm (2007) reviewed co-morbidity in children with LD and ASD and reported that diagnostic overshadowing is a significant problem and could be impacting on the lack of co-morbidity studies in this field.

1.4.4. Anxiety in Children with LD & ASD

1.4.4.1. Anxiety in Children with LD

Dykens (2000) and Lainhart (1999) both emphasise difficulty in estimating prevalence rates of anxiety in individuals with LD/ASD due to the variability in the methods used. These include IQ level, age, different sample groups (outpatient, community, inpatient), mixed etiological groups, different measures of psychopathology, and differences in diagnostic criteria. Additionally, Allen and Davis (2007) note that some papers use the terms 'psychopathology' or 'psychiatric disorder', which sometimes includes CB, or does not distinguish between different anxiety and mood disorders. However, various studies have been carried out which give an indication of the levels of anxiety experienced by children with LD and/or ASD.

Einfeld and Tonge (1996a and 1996b) carried out a series of studies with children with LD. Their results showed that 40.7% of their sample had severe emotional and behavioural problems, including anxiety. A large scale UK study by Emerson and Hatton (2007) compared children with LD to TD children. The main finding of this study was that the prevalence of psychiatric disorder was 36% among the children with LD, compared to 8% among the TD children. When looking at anxiety disorders specifically, the LD children had a prevalence rate of 11.4% compared to 3.2% in the non-LD children.

1.4.4.2. Anxiety in Children with ASD

There is general consensus in the literature that there is a high prevalence of anxiety in children with ASD. Studies involving prevalence rates have estimated that anxiety in children with ASD range from 43% to 84%, (e.g. Leyfer et al., 2006; Muris et al., 1998; Simonoff et al., 2008; Sukhodoldky et al., 2008). Anxiety in the ASD population has also been noted to be significantly higher than in TD populations (e.g. Farrugia and Hudson, 2006; Kim et al., 2000). The range of prevalence rates may again be due to methodological difficulties such as small sample sizes, lack of clarity regarding inclusion/exclusion criteria and the overlap of 'psychopathology' and 'psychiatric disorder' in some studies, (e.g. Einfeld and Tonge, 1996a &b).

1.4.4.3. Anxiety in Children with LD Compared to ASD

Due to the commonly used broad terms 'psychopathology' and 'psychiatric disorder', there are limited studies in the literature which compare LD and ASD

groups on levels of anxiety specifically. The few studies available suggest children and young people with ASD may experience more psychopathology than those with LD alone. For example, Brereton et al. (2006) and Carcani-Rathwell et al. (2006) examined psychopathology (which included anxiety) in children with ASD and found significantly higher levels of psychopathology in the ASD compared to the LD groups. Gillot and Standen (2007) examined anxiety specifically in an adult LD population and found significantly higher levels of anxiety in adults with ASD compared to LD alone. These studies suggest that broader psychopathology may be higher in individuals with ASD alone compared to LD alone. However, there is a lack of evidence regarding anxiety specifically, and also the impact of co-morbid ASD and LD on anxiety when compared to LD alone or ASD alone.

1.4.5. Aetiology of Anxiety in Children with LD and ASD

The evidence base suggests that children with LD and/or ASD show more anxiety than children in the TD population. Whilst there is no single definitive theory to explain why this is, there are several developmental/biological, psychological, and social factors which suggest why this may be the case.

1.4.5.1. Developmental/Biological Factors

Syndromes

There is some evidence to suggest that different syndromes associated with LD can impact on levels of anxiety. For example, Fragile X Syndrome (a genetic condition

caused by changes in the FMRI gene, and often accompanied by LD and ASD, ICD-10) has been linked to social anxiety and shyness (Bregman et al., 1988). William's Syndrome (a condition caused by deletion of genes from chromosome 7 and often characterised by specific facial features and LD, ICD-10) has been associated with fears and specific phobias (Dykens, 2000). Conversely, Dykens (2007) reported fewer emotional and behavioural difficulties in children with Down Syndrome (DS) compared to children with other syndromes, suggesting that links between syndromes and anxiety may be condition specific. Devine and Taggart (2008) suggest that whilst this research is in its infancy at present, advances in molecular genetics will allow for future studies to investigate these links further.

Dysregulation of neurotransmitters and abnormal regulation

The amygdala is part of the limbic system and is involved in emotion, behaviour and motivation (Kolb and Whishaw, 1996). Bellini (2006) examined social anxiety in children with ASD and speculated that children who are behaviourally inhibited (i.e. anxious children) have a lower threshold for arousal in the amygdala. This results in faster sympathetic nervous system responses (such as increased heart rate), when presented with a situation they find threatening, and more difficulties in controlling arousal levels. Similarly, Corbett et al., (2006) note that children with ASD have a dysfunction of the hypothalamic pituitary adreno cortical system, which results in increased cortisol levels when faced with a novel or threatening situation. This suggests physiological arousal will be more exaggerated in children with ASD, compared to TD children.

IQ

As noted previously, the cognitive impairments evident in children with LD result in difficulties with planning, sequencing and problem solving. This could result in difficulty selecting and implementing an appropriate coping strategy when faced with an anxiety provoking situation. This may increase the chances of withdrawal from situations (to relieve the anxiety) but limits the opportunity for learning adaptive coping strategies (Bellini, 2006). Additionally, Pearson et al. (2006) note that children with a mild LD in particular, may overestimate their abilities, and place themselves in challenging situations which they then find difficult to cope with.

1.4.5.2. Psychological Factors

Attachment

There is evidence to suggest that children with LD are more likely to develop insecure or disorganised attachments with their parents/caregivers (Van Ijzendoorn et al., 1999). These attachment styles increase the risk of anxiety, particularly when separated from the primary caregiver, most likely the parent (Bowlby, 1988). This could result in unhelpful interactions with the parent (e.g. excessive reassurance seeking) which may impact on parental stress and the ability to implement effective parenting strategies (Wallander et al., 2006).

Life Events / Exposure to Failure

Evans (1998) suggests that children with LD/ASD often have learning experiences which are dominated by failure, which can lead to anxiety and learned helplessness.

Furthermore, over the course of their lifetime, individuals with LD/ASD are likely to experience more negative life events, which has been found to contribute future psychological difficulties (Hurbert-Williams and Hastings, 2008).

1.4.5.3. Social Factors

Social Networks

Children with LD/ASD do not have the same social networks and friendships as TD children (Farrugia and Hudson, 2006; Greenham, 1999). Deficits in social skills and difficulty navigating social situations may also increase the risk of social stigma and peer rejection (Freeman and Kasari, 1998). Social networks are very important in acting as a 'buffer' to cope with stress and anxiety, so a lack of these may result in maladaptive coping strategies being adopted (Groden et al., 2006).

1.4.6. Summary

It seems clear that children with LD/ASD experience more psychopathology in general, including anxiety, than TD children. The exact prevalence rates and possible interaction between LD and ASD are unclear as very few studies have examined anxiety specifically, or do not examine LD+ASD in comparison to both LD alone and ASD alone. There are various developmental/biological, psychological, and social factors which may be pertinent to this finding. The next section will go on to discuss challenging behaviour in children with LD and/or ASD.

1.5. Challenging Behaviour

1.5.1. Introduction to CB

Challenging behaviour impacts greatly on the quality of life of the individual and other members of the family (Hastings, 2002). Individuals displaying CB could be at an increased risk of abuse, inappropriate treatment, neglect and exclusion from community and social situations (Emerson, 2001). CB (particularly aggression) is one of the primary reasons that a child may be moved out of the family home into residential care (Lowe et al., 2007). CB has also been noted to be linked directly to parental stress, over and above the core symptoms of the LD/ASD, (Baker et al., 2003; Hassall et al., 2005). It is therefore important to examine factors associated with CB and identify any which may predict levels of CB.

This section will provide a definition of CB, and studies examining CB in the LD/ASD population will be discussed. Relevant developmental/biological, psychological and social factors will then be highlighted.

1.5.2. Definition of CB

The term 'challenging behaviour' is used frequently in the literature to describe:

"...culturally abnormal behaviour of such intensity, frequency, or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to limit use of, or result in the person being denied access to, ordinary community facilities." Emerson (2001) p.3

It is also thought that in order to be defined as CB, the behaviour must cause impairment for the person by interfering with new skills, excluding learning

opportunities, and impairing quality of life (Emerson, 1998). Hartley et al. (2008) suggested that CB could be seen as internalised or externalised behaviour. The former could include emotional reactivity, withdrawal, or somatic complaints. The latter could include self injurious behaviour, destruction towards property, aggression towards others, or inappropriate social or sexual behaviour. CBs are often measured in terms of frequency, intensity and duration and multiple behaviours can often occur simultaneously (Matson et al., 2008).

1.5.3. CB in Children with LD & ASD

1.5.3.1. CB in Children with LD

The prevalence of CB in LD/ASD could appear to have increased over the past few decades as health care has improved (people with LD are living longer), and due to the closure of institutions and a shift to care in the community (Chung and Nolan, 1998). This shift results in CB being more visible to the public, which is likely to account for the apparent increase. However, it cannot be ruled out that a move out of institutional care with rigid structure and routine may in itself be challenging for some individuals (Chung and Nolan, 1998). It is a consistent finding in the literature that CB is significantly more common in children with LD/ASD compared to TD children (Baker et al., 2003). The exact prevalence of CB in children with LD is difficult to determine due to different assessment measures, subjective interpretation of behaviours, focus on either one or many different CBs and differences in identification of the sample (Emerson et al., 2001).

Despite these difficulties, recent studies have estimated that CB in children with LD ranges from 10% to 60%, (Adams and Allen, 2001; Emerson and Bromley, 1995; Emerson et al., 2001). Children with LD are often reported to engage in multiple forms of CB (Lowe et al., 2007). Additionally, Adams and Allen (2001) reported that carers of children with LD and CB are frequently injured during episodes of CB. These authors also comment that staff commonly report a lack of knowledge and skills regarding CB and have to "improvise" behavioural management strategies.

1.5.3.2. CB in Children with ASD

There is less evidence in the literature examining CB in ASD specifically, but there is still a general consensus that it is significantly higher than TD children. Hartley et al. (2008) examined CB in preschool age children and found that over one third of their sample had behaviours in the clinical range, indicating that CB is evident from a young age in children with ASD. Pilling et al. (2007) examined characteristics and experiences of children attending residential school, most of whom had a diagnosis of ASD. These authors found that over 90% of their sample displayed at least one form of CB. Whilst this high prevalence rate may not be surprising given that the participants attended residential school, the authors also noted the contact these children had with psychological services. They found that a very small minority of children had regular contact with psychology services, indicating that clinical input is not matching the difficulties being experienced in some areas. It is not clear, however, if this is due to a lack of resources in local services, or a lack of understanding from staff regarding CB and potentially helpful interventions.

1.5.3.3. CB in Children with LD Compared to ASD

There is very limited research that provides relevant information about the presence of ASD or the IQ level of the participants to enable a comparison of CB in LD and ASD. However, some studies have examined them together. McClintock et al. (2003) carried out a meta-analysis of 22 studies (6 including children) on risk factors of CB. Almost half of these studies included children with LD and ASD. The authors specifically investigated self injurious behaviour, aggression, stereotyped behaviour, and destruction of property. Findings suggested that male gender, severe LD, diagnosis of ASD, and poor expressive and receptive communication ability could all be risk factors for the studied CB. Murphy et al. (2005) investigated the chronicity of challenging behaviours in individuals with LD and/or ASD. Overall, these authors found that CB gradually reduced over time. However, the presence of a high score for CB at time two was predicted by the presence of CB, poor expressive language, poor social interaction and a diagnosis of ASD, at time one. These two studies suggest that CB is a chronic problem for children with LD and/or ASD. Furthermore, a diagnosis of ASD in addition to a diagnosis of LD may place a child at additional risk of CB.

1.5.4. Aetiology of CB

The evidence base suggests that there is a high prevalence of CB in children with LD/ASD, and this is detrimental to both the child and their family. Whilst there is no single definitive theory to explain why this is, there are several developmental/biological, psychological, and social factors which suggest why this may be the case.

1.5.4.1. Developmental/Biological Factors

Syndromes/Medical Conditions

There is some evidence to suggest that certain types of CB may be associated with specific syndromes. For example, Fragile X has been linked to hand biting and Smith Magenis (a syndrome caused by deletion of genetic material from chromosome 17 and is accompanied by LD, low muscle tone and distinctive facial features, DSM-IV) has been linked with head banging and nail pulling. Prader-Willi Syndrome (PWS) has been associated with self-injurious behaviour, temper tantrums and repetitive speech (Clarke et al., 1996; Dykens, 2000; Reddy and Pfeiffer, 2007). Schmitz (2006) suggests that anti-epileptic drugs can have side effects which include behavioural problems and affective disorders.

IQ

The majority of evidence regarding the impact of IQ on CB suggests that the more severe the LD, the more severe the CB, but this has not always been consistent. The previously discussed meta-analysis by McClintock et al. (2003) and a study by Emerson and Bromley (1995) both suggested that more severe LD was associated with higher levels of CB. Similarly, Hartley et al., (2008) reported that a significant amount of the variance in CB was accounted for by non-verbal cognitive ability and adaptive behaviour, suggesting more severe LD was associated with more severe CB. In contrast to these findings, Emerson et al. (2001) reported that aggression was shown by individuals with less severe LD, whereas self injury was displayed by

individuals with more severe LD. This suggests that there is possibly a complex relationship between the form of CB and severity of LD, but limited literature addresses this relationship.

1.5.4.2. Psychological Factors

Positive and Negative Reinforcement

In their Clinical Practice Guidelines for individuals with severely CB, the British Psychological Society state that CB is a product of the person, their environment, the behaviour and the interactions between these three elements, (British Psychological Society, 2004). Challenging behaviour can be maintained for a variety of reasons, but can often be due to positive or negative reinforcement, which is (often unknowingly) given by the caregiver. The former is the presence of a positive event, such as social interaction, and the latter is withdrawal of a negative event, such as removal from task demands. CB could also be maintained by internal or automatic consequences such as sexual pleasure, deflection of pain or sensory stimulation (Emerson, 1998). The reinforcement or maintenance of behaviours will vary within and between individuals and the same behaviour is likely to serve different functions for different people. For example, head banging could be used to gain social interaction, be removed from a situation or to indicate or deflect pain. The course of a CB may also change over time, meaning that what initiated it may not be maintaining it. For example, eye poking could have been initiated to gain visual stimulation, but be maintained by social interaction.

Stress and Attachment

Janssen et al. (2002) proposed a stress-attachment model of CB in LD. Individuals with LD are susceptible to developing insecure attachments (particularly disorganised) due to parental stress, ineffective parenting and the child's limited cognitive skills (Van Ijzendoorn et al., 1999). Attachment figures should provide security and help to regulate the emotions and behaviours of a child. Stress is defined as when the threat of the situation is deemed to be greater than the resources to meet the demands of the threat and this is accompanied by physiological arousal. Individuals with LD are particularly vulnerable to stress due to limitations in appraising and processing information in a situation (Emerson, 1998). Ongoing stress can leave the individual in an almost permanent state of activation, without the coping skills necessary to regulate their emotions. Janssen et al. suggest that this produces CB in individuals with LD. Clegg and Sheard (2002) suggest that the impact of insecure attachments on CB can persist into adulthood.

Parental Factors

Baker et al. (2003) examined stress in parents of pre-school children with behaviour problems, with and without developmental delay. These authors found that child behaviour problems and parenting stress have a mutually escalating effect on each other, suggesting that the parenting environment interacts with the child's behaviour, which in turn interacts with the parenting environment. In addition to this, parenting stress was found to be related to the child's behaviour as opposed to the child's level of intellectual functioning.

1.5.4.3. Social Factors

Communication

Research has paid particular attention to the possibility that communication difficulties may be an integral part of CB in an LD/ASD population. It has been assumed that due to their impairments in communication, children with LD and/or ASD may use CB as a method of communication. As noted previously, McClintock et al. (2003) reported that deficits in receptive and expressive communication were a risk factor for CB. Chiang (2008) conducted a large study involving naturalistic observations of children with ASD and LD. Over half of the children observed displayed CB, and it was believed that this was produced mainly as a means of requesting or rejecting interaction from either staff or peers. In the aforementioned study by Hartley et al. (2008) it was found that low expressive language ability was a risk factor for inattention and internalising problems, which led the authors to conclude that some CB may be an inappropriate means of communication.

1.5.5. Summary

Children with LD and/or ASD experience more CB than TD children. The exact prevalence rates are unclear due to differences in sample identification and definition of CB. Additionally, it is possible that a diagnosis of ASD may lead to increased CB when combined with a diagnosis of LD. There are various developmental/biological, psychological, and social factors which may contribute to the high prevalence rate of CB in children with LD and/or ASD overall, and the additional vulnerability to CB when both diagnoses are present. The next section will go on to discuss the relationships between sleep problems, anxiety and CB.

1.6. Relationships Between Factors

It seems clear from the literature discussed above that sleep problems, anxiety and CB are difficulties experienced by many children with LD and/or ASD and these factors have a negative impact on the children and their families. The following section will examine the relationships between these factors. Sleep problems and anxiety will be discussed first, followed by sleep problems and CB, and finally anxiety and CB. Where there is limited research carried out in the child LD/ASD population, studies in the TD child or adult LD/ASD populations will be discussed.

1.6.1. Sleep and Anxiety

1.6.1.1. Introduction to Sleep and Anxiety

There has been a substantial volume of research examining sleep problems and anxiety in TD children, but far less has been dedicated to the relationship between sleep problems and anxiety in the child LD/ASD population. Given the consistent relationship found in the TD population, it seems reasonable that a similar relationship would be found in the LD/ASD population. This section will examine some literature from the TD population and then discuss the limited research from the LD/ASD population. Finally, the developmental/biological, psychological and social factors previously discussed will be reviewed to suggest how these factors might interact in the LD/ASD population.

1.6.1.2. Sleep and Anxiety in TD Children

There is a wealth of literature examining the relationship between sleep problems and anxiety in TD children. For example, Ivanenko et al. (1999) looked at previous diagnoses of children referred to a sleep clinic for insomnia, and found 65% had a previous or current anxiety disorder. Alfano et al. (2006) investigated sleep and anxiety in children referred for anxiety, children referred for sleep problems, and healthy controls. Sleep problems were significantly higher in the sleep problem and anxiety group compared to the control group. Intermittent sleep problems were evident in 83% of the anxiety group, and over half of this group reported regular sleep problems. Age did not impact on the results, as similar findings were evident when the samples were divided into children and adolescents.

A more recent study by Alfano et al. (2007) examined the prevalence of sleep problems in children and adolescents with anxiety disorders. Results showed that 88% had at least one sleep problem, and 55% had 3 or more sleep problems. The authors suggested a reciprocal relationship between sleep and anxiety. Similarly, El-Sheikh et al. (2007) found that emotionally secure children showed more consolidated sleep than emotionally insecure children. Additionally, the authors found that poor sleep quality had a negative impact on the child's behaviour, emotion, and academic performance.

Chorney et al. (2007) examined the literature on sleep, anxiety and depression in TD populations. Overall, these authors found that the literature reports positive correlations between sleep problems and psychopathology, but note that correlation does not determine causation. The authors also suggested that more rigorous

methodologies are required for future research as current studies have used vague terminology, have not been clear in inclusion and exclusion criteria and have not made outcome variables clear (e.g. Alfano et al., 2007).

1.6.1.3. Sleep and Anxiety in Children with LD and ASD

There is a lack of literature on the relationship between sleep problems and anxiety in children and young people with LD and/or ASD. Patzold (1998) suggested that psychological factors such as anxiety may be impacting on sleep problems, but this is not directly addressed. Allik et al. (2006) reported a positive correlation between the emotional subscale of the Strength and Difficulties Questionnaire (SDQ, comprising of 5 items) and insomnia in an ASD population. Whilst this suggests a relationship between emotional difficulties and sleep problems in children with ASD, it does not address anxiety specifically. Zarowski et al. (2006) conducted a study examining anxiety and sleep in children and young people, and although it was not using an LD population specifically, it included children with a lower than average IQ. These authors found a significant relationship between sleep problems, anxiety and impulsivity overall, and a significant relationship was found between anxiety and sleep disturbance in the low IQ group (IQ under 90). Whilst this suggests that the sleep and anxiety relationship may be evident in the lower IQ population, it has not been examined in the LD and ASD population specifically.

1.6.1.4. Developmental/biological, psychological and social factors

The developmental/biological, psychological and social factors which may lead children with LD/ASD to be more vulnerable to sleep problems and anxiety have

already been discussed. However, it is important to consider how these factors may overlap or interact to lead to an expected relationship between sleep problems and anxiety in the LD/ASD population.

Anxiety is known to be accompanied by physiological and cognitive arousal. This involves activation of the sympathetic nervous system and neurochemical changes, including an increase in adrenaline, serotonin, cortisol and anxiety related thoughts (El-Sheikh et al., 2008; Fisher and Rinehart, 1990). It is unclear whether individuals with a severe LD would be able to access these cognitions, but it is likely that individuals in the milder range would (Couturier et al., 2005). Physiological and cognitive hyperarousal, (in combination or individually) do not allow a basis for restful sleep. As noted previously, it is unclear whether sleep problems lead to anxiety or vice versa and it is likely that the relationship will be bi-directional (Alfano et al., 2006).

Sleep deprivation for parents can interfere with family functioning and impair the resources that parents have to effectively address the child's sleep problem or anxiety. This could result in unhelpful reinforcement (e.g. allowing child to sleep in parent's bed), resulting in a routine which will cause anxiety and disrupted sleep if parents try to change it (Hoffman et al., 2008).

Insecure attachments can lead to separation anxiety and impaired self regulation skills. This could impact on both sleep and anxiety as the child is likely to be distressed when separated from parents (whether that is at bedtime or during the day)

and is unlikely to develop adequate self-soothing skills to help regulate their own emotions. Additionally, if considering the theory of mind hypothesis in relation to children with ASD, it is possible that children may find difficulty recognising their own internal state, whether that is in terms of sleepiness, anxiety, or both.

Communication skills may also impact on both sleep and anxiety, as a child with LD/ASD may be unable to express themselves to allow their needs to be met. This could be something simple such as being too hot in bed, or something more complex such as a worry about school.

1.6.1.5. Summary of Sleep and Anxiety

A strong relationship has been shown between sleep problems and anxiety in the TD child literature. There is some limited evidence to suggest that this relationship is also evident in the child LD/ASD literature. Given the relationship shown in the TD child literature and the aforementioned developmental/biological, psychological and social factors which may interact in the child LD/ASD population, it is important to investigate if this relationship is evident in the LD/ASD population.

1.6.2. Sleep and CB

1.6.2.1. Introduction to Sleep and CB

There is some evidence to suggest that there is a relationship between sleep problems and behaviour problems in TD children (e.g. Blunden and Chervin, 2008; Stein et al., 2001). Given the higher prevalence of CB specifically in the LD/ASD literature, it is

unsurprising that there is substantial evidence to suggest a relationship between sleep and behaviour in children with LD/ASD. This section will highlight current literature regarding this relationship, and the developmental/biological, psychological and social factors previously discussed will be reviewed to suggest how these factors might interact in the LD/ASD population.

1.6.2.2. Sleep and CB in Children with LD and ASD

There is considerable evidence in the literature to suggest a relationship between sleep problems and challenging behaviour in children and young people with LD and/or ASD. An early study by Wiggs and Stores (1996) examined severe sleep problems and daytime CB in children with severe LD and found that children with sleep problems showed a greater number of types of CB. Furthermore, the CB was at a greater severity than in the children without sleep problems. The authors found that children who showed poor sleep were more likely to show daytime irritability, lethargy, stereotyped behaviour and hyperactivity. They suggested that the disrupted sleep had a direct impact on daytime functioning. This study also showed that 16.5% of their sample had an ASD diagnosis and 68% of the ASD children had current mental health difficulties, but did not go further in explaining any possible differences between the children with ASD and LD. A similar study was conducted by Brylewski and Wiggs (1999), but used adults with LD. These authors divided the sample into good sleepers and poor sleepers and found that the poor sleepers showed significantly more CB, including daytime irritability, stereotyped behaviours, and hyperactivity. This suggests that the difficulties seen in childhood are likely to continue into adulthood.

Richdale et al. (2000) explored stress, behaviour and sleep problems in 52 children with LD/ASD compared to healthy controls. Findings suggested that the presence of sleep problems was significantly associated with intensity and frequency of parental hassles and the presence of CB. The level of LD was not found to impact on the findings. The authors noted that whilst a relationship was found between sleep and CB, no direction could be predicted. They suggested that more research is required to gain a better understanding of this relationship. Didden et al. (2002) also examined sleep problems and daytime behaviour in children with a range of levels of LD. Just over one fifth of this sample also had ASD. Results suggested that the children with severe sleep problems also showed higher scores on aggression, screaming, temper tantrums, non-compliance and impulsivity compared to the children without a sleep disorder. The authors also noted that the children with more severe LD had more severe sleep problems and suggested that psychological factors such as anxiety could be involved, but this was not investigated. They also did not examine the data in terms of LD and ASD groups.

A more recent study by DeVincent et al. (2007) compared preschool children with and without PDD on measures of sleep and behaviour. A relationship was found between sleep and behaviour in both groups and the authors highlighted the fact that this relationship was similar between the two groups. However, significantly more sleep problems were evident in the PDD group and these were associated with inattentiveness, hyperactivity and oppositional behaviour. Children in the sleep

disturbance group also showed more elevated scores on scales of separation anxiety, generalised anxiety disorder, and major depressive disorder.

1.6.2.3. Developmental/Biological, Psychological and Social Factors

The developmental/biological, psychological and social factors which may lead children with LD/ASD to be more vulnerable to sleep problems and CB have already been discussed. However, it is important to consider how these factors may overlap or interact to lead to an expected relationship between sleep and CB in the LD/ASD population.

The previous research by Wiggs and Stores (1996) and Brylewski and Wiggs (1999) suggest three possible associations for the relationship found between sleep and CB. Firstly, they suggest that sleep problems are a form of CB. They speculate that refusal to go to bed or a delay in going to sleep could be seen in itself as CB, and not a separate sleep problem. Secondly, they suggest that sleep problems cause daytime behaviour problems and/or contribute to their maintenance. The loss of REM sleep found in children with LD/ASD is thought to impair the learning process, which is already challenging for these children (Brandon and Zee, 2006). This could impact on the child's ability to learn academically, but also on their ability to learn adaptive and appropriate coping strategies. Lack of sleep at night has also been shown to lead to either daytime sleepiness or hyperactivity in children (Hoban, 2000), neither of which provide a suitable environment for a child to learn or for a parent to teach appropriate behaviour. Parents may unknowingly reinforce both sleep and CB problems, and high stress levels make it difficult to be consistent in setting

boundaries. Thirdly, they suggest that both are connected to the underlying pathology of LD and ASD. This could include communication difficulties as CB has been suggested to be a maladaptive way of communicating. The authors suggest that there is no definitive explanation as to the relationship as yet, and further research is required.

1.6.2.4. Summary of Sleep and CB

There is substantial evidence to suggest that there is a relationship between sleep and CB in the child LD/ASD population; however, many studies have looked at LD and ASD as one group, which has not allowed the potential differences between LD and ASD children to be explored. Additionally, many studies have been correlational, which has not allowed further exploration into the nature of the relationship. Suggestions have been made as to why this relationship may exist, but further research is needed to understand it in more detail.

1.6.3. Anxiety and CB

1.6.3.1. Introduction to Anxiety and CB

There is a distinct lack of research into the relationship between CB and anxiety in children with LD and/or ASD. However, there is considerable evidence in the adult LD/ASD literature. We can speculate (with caution), that given the consistency between the child and adult literature mentioned previously, the same consistency may be found for the relationship between CB and anxiety. As noted previously, much of the adult literature examines 'psychopathology' as a whole (which will

include anxiety) but few studies investigate anxiety specifically. However, given the inclusion of anxiety in these studies and overlap between anxiety and mood disorders, this literature is still valuable in gaining insight into the possible relationships between these factors in children with LD and/or ASD.

1.6.3.2. Anxiety and CB in Individuals with LD and ASD

Bradley et al., (2004) conducted a study involving adolescents and young adults with ASD plus LD, or LD alone, and examined the relationship between emotional and behavioural disturbance. Results showed that whilst this relationship was evident in both groups, it was significantly greater in the ASD plus LD group. The ASD plus LD group showed significantly higher scores on anxiety, mania, depression, stereotypies, sleep disorders and organic syndromes. Emotional and behavioural problems were four times higher in the ASD plus LD group and a significant relationship was found between emotional and behavioural problems. However, the authors noted that results must be interpreted with caution due to the small sample size, and the authors use the term 'emotion' to cover a wide range of feelings, one of which is anxiety.

Allen and Lowe (2006) conducted a large scale study involving adults with LD. They found that the full sample showed some form of CB and over 23% had a formal diagnosis of a psychiatric disorder. A further 20% reached the threshold for psychiatric diagnosis, suggesting that almost half of the sample had some form of psychological distress. Whilst not examining anxiety specifically, the authors reported a positive correlation between emotion and CB.

Holden and Gitlesen (2008) examined psychopathology and CB in adults with LD. Their findings revealed that 71.4% had one or more symptoms of psychiatric disorder, and CB included self injury (21%) and attacking others (30.3%). Analysis of the function of the CB included automatic reinforcement (27.7%), escape from demands (33.6%), tangible reinforcement (31.9%) and attention (20.2%). These authors found a relationship between total psychopathology and total CB, but did not find a specific relationship regarding the function. They therefore concluded that the function of a CB cannot be predicted on the basis of psychiatric symptoms. Due to undocumented psychometric properties of the instrument used, the authors noted that subscales could not be analysed, resulting in less detail about anxiety specifically.

Hemmings et al. (2006) examined the relationship between CB and psychiatric symptoms in adults with LD/ASD. These authors found that self injury and aggressive problem behaviours were mostly associated with affective type symptoms and the presence of ASD increased the risk of certain problem behaviours such as screaming. Again, these authors did not examine anxiety specifically, but did note that the presence of the symptom 'fearful/panicky' was significantly associated with the behaviour 'pester/seeks attention'. These authors suggested that problem behaviours are underpinned by psychiatric disorders in a proportion of individuals with LD.

Myrbakk and von Tetzchner (2008) also investigated the relationship between psychiatric disorder and behaviour in adults with LD. The authors note that due to

the high numbers of individuals with LD who do not display CB, there must be an additional factor that contributes to the development of CB. Myrbakk and von Tetzchner's study was a total population study and participants were divided into problem behaviour and no problem behaviour groups. Results showed that 69% of the behaviour problems group scored above cut off on all psychiatric scales (which included anxiety) compared to 29% of the non problem behaviour group. When comparing different levels of LD, more psychiatric symptoms were seen in the mild/moderate group in comparison to the severe/profound group. The authors suggested that CB may be a display of unconventional psychiatric symptoms. A significant relationship was found between levels of anxiety and aggression, tantrums, screaming and self injury. The authors did not specify if any of the participants also had ASD.

1.6.3.3. Developmental/Biological, Psychological and Social Factors

The developmental/biological, psychological and social factors which may lead children with LD and/or ASD to be more vulnerable to sleep problems and CB have already been discussed. However, it is important to consider how these factors may overlap or interact to lead to an expected relationship between sleep and CB in the LD/ASD population.

There are various ways to interpret the relationship between anxiety and CB. It is possible that CB may be an atypical presentation of psychiatric disorder, as in a behaviour equivalent of a psychiatric symptom (Hemmings et al., 2006). Sullivan et al. (2007) explored this idea, looking specifically at children with Fragile-X

Syndrome. The authors reported that the children who were less able to communicate their day to day worries and anxiety showed increased observable behaviours such as arguing and aggression, and that children showing high levels of generalised anxiety disorder showed high levels of obsessive compulsive behaviour.

Allen and Davis (2007) suggested that CB could occur secondary to a psychiatric disorder. An example of this could be refusal to attend school, which in turn may be viewed as non-compliance and as a CB, but may actually be a result of the child's anxiety in attending school. If the child succeeded in not attending school, this could lead to negative reinforcement (i.e. removal of the undesired event), and maintain the behaviour viewed as challenging. Similarly, the authors suggested that psychiatric disorder could be viewed as a 'setting event' for CB to occur. If this is considered in light of previously discussed insecure attachment in children with LD/ASD, a child who is anxious about being separated from their parents may engage in behaviours to stay close to the parents or seek excessive reassurance from them, which could be interpreted as being challenging. Again, reinforcement of these behaviours may occur if they result in the desired outcome.

The previously discussed communication difficulties, and difficulty in understanding one's own internal state in children with LD/ASD, may again contribute to this association between anxiety and CB. If a child is having difficulty recognising internal feelings and emotions, communication difficulties may lead to problems labelling feelings and also impair the child's ability to access whatever help they need. This may then result in CB as a means of communicating their needs.

1.6.4.4. Summary of Anxiety and CB

The research around the relationship between anxiety and CB comes mainly from the adult LD/ASD literature, showing a gap in the child LD/ASD research. However, it could be speculated that given the consistency between other adult and child literature, it could be expected that a relationship between anxiety and CB will be found in the child LD/ASD population. Some suggestions have been made as to why this relationship may exist, but whilst the understanding of the nature of the relationship is in its infancy, further research is needed.

1.7. Aims of this Study

There is a substantial amount of literature that suggests that sleep problems, anxiety and CB are significantly more common in children with LD and/or ASD than in TD children. Although there has been some conflicting evidence in previous studies, it appears that having an ASD as well as a LD may lead to increased difficulty in these areas. The research to date looking at the relationship between sleep problems and anxiety is predominantly in the TD child population and this firmly shows a positive relationship between sleep problems and anxiety. Whilst a minority of studies have suggested that this relationship may be present in a child LD/ASD population, this relationship does not appear to have been examined directly. The relationship between sleep problems and CB is fairly well established in the child LD/ASD literature, but often does not separate clinical populations into LD alone, LD plus ASD, and ASD alone subgroups, leaving a gap in our understanding of this

relationship. The research to date examining the relationship between anxiety and CB is primarily in the adult LD literature and is distinctly lacking in the child LD/ASD population. In addition to this, many studies have examined 'psychopathology' or 'psychiatric disorder'. This may take anxiety into account, but does not examine it specifically. Many authors have commented on the correlational relationship between anxiety and CB, but note that whilst this indicates an association, further information is required to understand these relationships in more detail.

The research to date indicates associations between sleep and anxiety, sleep and CB, and anxiety and CB. However, it appears that these three factors have not been examined together. Given the associations found in combinations of two of these three factors, it seems reasonable to assume that the three factors may further interact together and an understanding of this would help to inform clinical research and practice. Furthermore, many previous studies have commented on the lack of understanding of the relationships between these factors and the need for further exploration beyond correlational studies. Therefore, this study intends to further the research conducted on sleep, anxiety and CB by examining the relationships between all three factors.

Firstly, this study aims to find out if the co-existence of LD plus ASD results in more difficulties in the areas of sleep problems, anxiety and CB than in LD alone or ASD alone. Secondly, the study aims to examine if there is a relationship between sleep problems and anxiety, sleep problems and CB, and CB and anxiety in children with

LD and/or ASD. Thirdly, the study aims to explore to what extent sleep problems and anxiety predict CB.

1.8. Hypotheses

Hypothesis 1: Sleep problems, anxiety and CB will be significantly higher in the LD+ASD group, compared to the LD alone and ASD alone groups.

Hypothesis 2: There will be a significant positive correlation between sleep problems and anxiety in children with LD and/or ASD.

Hypothesis 3: There will be a significant positive correlation between sleep problems and challenging behaviour in children with LD and/or ASD.

Hypothesis 4: There will be a significant positive correlation between anxiety and challenging behaviour in children with LD and/or ASD.

Hypothesis 5: Sleep problems and anxiety will account for a significant amount of the variance in relation to challenging behaviour in children with LD and/or ASD.

Chapter 2: METHODOLOGY

2.1. Design

This study used a quantitative, within and between subjects, questionnaire based design. Three variables were measured: sleep problems, anxiety and challenging behaviour (CB). The design was cross sectional as it captured data on a clinical group at one time period. A multiple regression analysis was performed using Statistical Package for Social Sciences (SPSS), Version 13.0 with CB as an outcome, on the basis of predictors: medication use, sleep problems and anxiety[1].

2.1.1. Site of the Study

This study involved four health boards across Scotland. One or two on-site representatives were recruited in each region to assist in the identification of potential participants. These individuals comprised professionals from Clinical Psychology, Child and Adolescent Mental Health Services, and Community Child Health.

[1] Hypothesis 5 states that the variance in CB accounted for by sleep problems and anxiety will be investigated. However, the analysis reported in Chapter 3 revealed that medication use should be added to the model. This Methodology Chapter was therefore adapted to ensure that the inclusion of the extra predictor variable (i.e. medication) was incorporated into the description of the design and power calculation.

2.2. Ethical and Design Considerations

A number of steps were taken to address ethical and design issues during the planning of this study.

2.2.1. Ethical Approval

Ethical approval for all sites was sought from the University of Edinburgh Research and Ethics Committee and from the local Committee on Research Ethics (Rec. Ref. No. 09/S1402/4 – See Appendix I). Minor changes were made to the information sheet (re-structuring of the information and providing more background information) and letter of invitation (introductory paragraph and inclusion of the name of the on-site representative for each region), and these were accepted on resubmission. Research and Development approval was sought for each region and co-ordinated through NHS Research Scotland. Queries regarding confidentiality and supervisor time were explained, and approval was given by each region. Caldicott approval was also sought for each region, as the study required access to patient identifiable information to obtain addresses, IQ scores and method of ASD diagnosis, where available.

2.2.2. Parental Report

The study aimed to collect information about children and young people with LD and/or ASD. However, it was felt that asking these individuals directly could be problematic. They may not have the ability to complete self report measures, be unreliable in reporting, and in addition to this, may not have the capacity to give

informed consent. It was therefore felt that using parental report would be a more appropriate means of gathering the required information. As the parent or guardian of the child or young person, they could judge whether or not they would like to consent to providing the required information. However, it must be noted that this method relies on the parent's subjective interpretation of their child's difficulty.

2.2.3. Diagnostic Issues

It was found that previous research often reported the level of LD of the participants, either as an IQ score, or as a category (i.e. mild/moderate/severe). Through discussion with the on-site representatives, it was apparent that the clinical population being sampled would not routinely have undergone cognitive assessment. The prospect of carrying out a cognitive assessment on each of the children whose parents returned the questionnaire pack was considered. However, it was felt that this was not appropriate as it would not be carried out for clinical reasons, it could be anxiety provoking for the child or young person and would be time consuming. As an alternative, it was decided that it was probable that the child would meet diagnostic criteria for LD if they were already known to the LD service, and IQ scores could be recorded for those who had previously undergone a cognitive assessment to provide sample characteristics. It was intended that in the majority of cases the diagnosis of ASD would have been obtained using procedures recommended by SIGN, including the Autism Diagnostic Observation Schedule (ADOS) and/or Developmental, Dimensional and Diagnostic Interview (3DI) and assessed by a multi-disciplinary team (MDT). This would include all categories

within the DSM-IV and ICD-10 of Pervasive Developmental Disorders, as discussed in section 1.2.4.

2.2.4. Medication

The possibility of excluding children who were taking medications that may impact on sleep, anxiety or CB was discussed. However, it was decided that it was not appropriate to do so in this case. The study aimed to capture a realistic clinical sample of children and young people who present to clinical services, therefore inclusion of children on all medications was deemed appropriate. In addition to this, there were concerns that excluding this data could mean a significantly lower amount of usable data, which could be detrimental to the power of the study. Previous similar studies have included children on medication (e.g. Schreck & Mulick, 2000). It was decided to ask parents to note in the demographic information sheet if their child was on medication. This way it would be possible to report if the sample could potentially be biased, and control for this in the analysis if necessary.

2.2.5. Medical Conditions and Syndromes

The possibility of excluding children with medical conditions or syndromes was discussed while designing the study, but again it was felt that in order for the sample to be representative of a realistic clinical population, it was important to include these individuals. Previous similar studies have included children with various medical conditions and syndromes (e.g. Cotton and Richdale, 2006). Again, parents were asked to indicate on the demographic information sheet if their child had any medical diagnoses or particular syndromes.

2.3. Participants

Participants in the study were parents/guardians of children and young people with LD and/or ASD. They were recruited from the LD/ASD service within Child and Adolescent Mental Health Services, Community Child Health, and Clinical Psychology in four NHS Health Boards in Scotland. Inclusion criteria for the parent/guardian was that they were over 18 years old, were the main caregiver of the child and had the ability to read, understand, and respond to the questionnaires.

The age range of 5-18 years for the children with LD/ASD was chosen as this has been used in previous studies (e.g. Keenan et al., 2007 and Wallander et al., 2006). Previous studies often examine either pre-school or school age children, and given the natural difficulties with sleep in pre-school children, the decision was taken that age 5 was an appropriate lower age limit. Many young people remain in Child and Adolescent Services until age 18, if they are in education. In order to capture a realistic clinical sample, this was used as the upper age limit. As noted previously, it could not be definitively assessed if all of the children met the criteria for a LD outlined by the DSM-IV or ICD-10, but this is suggested by their inclusion in the LD service in their region. Children with medical conditions and syndromes, and on medication, were included in order to gain a realistic clinical sample. No children who met the inclusion criteria were excluded, unless an on-site representative felt that participation in the study was inappropriate (e.g. if the parents were already involved in other research studies).

2.4. Materials

The materials used in this study were a letter of invitation, participant information sheet, consent form, demographic information sheet, and three standardised questionnaires, specifically: The Child's Sleep Habits Questionnaire (CSHQ-Owens et al., 2000); The Aberrant Behaviour Checklist-Community (ABC-C-Aman and Singh, 1994); and The Spence Children's Anxiety Scale – Parental Version (SCAS-P-Nauta et al., 2004; Spence, 1998).

2.4.1. Letter of Invitation

The letter of invitation began with an introductory paragraph introducing the multi-site and collaborative nature of the study. It then described the study and explained the materials contained in the pack. It was co-signed by the on-site representative, and on the headed paper of each region. This is displayed in Appendix II.

2.4.2. Participant Information Sheet

A participant information sheet was developed in order to provide details about the purpose of the study, how and where the data would be stored, and how it would be used. It was made clear that current or future service provision to the participants' children would not be affected in any way by their choosing to take part or not. It was also highlighted that the study aimed to gather information about children and young people who did, and did not, experience the difficulties being examined. It was hoped that this would encourage an unbiased sample. The risks to participants were thought to be minimal, but these were explained to the participants and advice

to obtain further support was given. Contact details were also provided in case the participants had any questions or concerns. Participants were also informed that their responses would be made anonymous on return. Data was stored in a locked filing cabinet on secure NHS premises, and all patient identifiable information was destroyed on completion of the study. This is displayed in Appendix III.

2.4.3. Consent Form

The consent form was produced in line with the guidance supplied by the local Research Ethics Committee. It also asked participants to provide their contact details if they requested feedback on the results of the study. This is displayed in Appendix IV.

2.4.4. Demographic Information Sheet

This information sheet asked participants to provide information regarding their relationship to the child, the child's gender, age, medical conditions, medication, and if they knew their child to have a diagnosis of LD and/or ASD. This allowed characteristics of the sample to be recorded, and also to indicate if the sample could possibly be biased due to high numbers of children taking medication and/or with a specific medical condition or syndrome. This is displayed in Appendix V.

2.4.5. The Child's Sleep Habits Questionnaire

This questionnaire was designed for parental report of sleep habits of school age children (Owens et al., 2000). The 33 items are rated on a 3 point scale, and encompass key sleep domains which represent the sleep problems found in children

in this age group. The CSHQ has 8 subscales: bedtime resistance; sleep onset delay; sleep duration; sleep anxiety; night wakings; parasomnias; sleep disordered breathing; daytime sleepiness. A total score of 41 has been noted as signifying individuals with sleep problems, and has been found to be valid and test-retest reliability in the range of 0.62 - 0.79 (Owens et al., 2000). Whilst it was not designed specifically for use with individuals with LD/ASD, it has been used in previous studies examining this clinical group (e.g. Couturier et al., 2005; Hoffman et al., 2008; Honomichl et al., 2002). An adolescent version of the CSHQ has been developed, but has not yet been validated. Through personal correspondence with the author, it was recommended that this study use the school age version of the CSHQ for the full sample, irrespective of age, and that it would be suitable to use with this population. This is displayed in Appendix VI.

2.4.6. The Spence Children's Anxiety Scale – Parental Version

The SCAS is a well established measure of child anxiety and has a child and a parent version, (Spence, 1998). The parent version only is being utilised in this study. The 38 items are rated on a 4 point scale. The measure yields 6 subscales: separation anxiety; generalised anxiety; social phobia; panic/agoraphobia; obsessive compulsive disorder; fear of physical injury. Means and standard deviations are provided for males and females of different ages to allow identification of clinical levels of anxiety. The SCAS-P has been found to have high validity and reliability, and consistency has been found between child and parent versions, (Nauta et al., 2004). There are no questionnaire parental report measures of anxiety specifically for children with LD/ASD, however, the SCAS-P has been used previously in studies in

ASD, (e.g. Gillott and Standen, 2007; Sofronoff et al., 2005). This is displayed in Appendix VII.

2.4.7. The Aberrant Behaviour Checklist-Community

This questionnaire is an informant based measure of CB (Aman and Singh, 1994), and is an adaptation of the original Aberrant Behaviour Checklist that was designed for use with individuals with LD in residential accommodation (Aman and Singh, 1986). The 58 items are measured on a 4 point scale. Five factors have been identified in this measure: irritability; aggression and crying; lethargy and social withdrawal; stereotyped behaviour; hyperactivity and non-compliance; inappropriate speech. There are no formal cut-off scores for this measure, although Aman & Singh (1994) report that scores falling within the 85th percentile can be defined as clinically significant. This measure was initially designed for use with adults with LD, although it has been used with children with LD and the factor structure, reliability and validity was maintained (Marshburn and Aman, 1992; Rojahn and Hesel, 1991). Other studies using the ABC-C with children with LD/ASD include Wiggs and Stores (1996) and Didden et al. (2002). This is displayed in Appendix VIII.

2.5. Procedure

The Principal Investigator and her clinical supervisor met with on-site representatives in each region to discuss the study and the identification of potential participants. Names and addresses of potential participants were identified from clinical case loads and departmental databases. Names and addresses of children

fitting the inclusion and exclusion criteria were passed on to the Principal Investigator, and questionnaire packs (previously described) were sent directly to the parents/guardians. Participants were asked to return the questionnaires to the Principal Investigator within a four week period.

Individuals who chose to participate completed the consent form, demographic information sheet, and three questionnaires, and returned them directly to the Principal Investigator in the stamped addressed envelope provided. On return, consent forms and questionnaires were marked with an identifier (i.e. a corresponding number). The consent forms were then separated from the questionnaires and held in a separate location, thereby making the data on the questionnaires anonymous. On completion of the study, all patient identifiable information was destroyed.

2.6. Data Analysis and Power Calculations

All analyses were conducted using the SPSS Version 13. Hypothesis one was tested using One-Way Analysis of Variance (ANOVA), to identify if group category (i.e. LD, LD+ASD, ASD) significantly impacted on the measures of sleep problems, anxiety, and CB. Hypotheses two, three and four were tested using the Pearson correlation to identify the relationships between sleep problems, anxiety, and CB. A hierarchical multiple regression was then carried out to test hypothesis five, with CB as the outcome variable and medication, sleep problems and anxiety as the predictor variables.

Power calculations and effect sizes are rarely reported in literature around sleep problems, anxiety and CB. One exception is Couturier et al. (2005) who noted a medium effect size in an investigation into sleep problems in children with PDD. Additionally, Cohen (1992) suggests that overall, most effect sizes from psychological research are medium. On this basis, power calculations were carried out with a power level of 0.8 and alpha level of 0.05 to determine how many participants were required for a medium effect size for each statistical test used. According to Cohen (1992), 52 participants in each group are required for an ANOVA, 85 participants are required overall for Pearson correlations and 76 participants are required for multiple regression analysis with three factors (i.e. medication, sleep problems and anxiety).

Chapter 3: RESULTS

3.1. Sample Characteristics

Six hundred and thirty four questionnaire packs were sent to parents/guardians of children with a diagnosis of LD and/or ASD. One hundred and eighty seven were returned (return rate 29%). However, 20 of these were only partially complete. Due to the amount of missing data in the partially completed questionnaires, it was decided that these would not be included in the analysis. Therefore, 167 complete data sets were analysed. Unfortunately it was not possible to carry out any comparison of respondents and non-respondents due to a lack of information about the non-respondents.

The mean age of the participants was 11.3 years (Std Dev = 3.13; Range = 5-18 years). Demographic information regarding gender, relationship of respondent, co-morbid medical/developmental disorder, sensory problems, medication status, and group category are displayed in Table 3.1. below:

Table 3.1. Demographic Information for the Sample (n=167)

Variable	**Information**	
Gender	Male	137 (82%)
	Female	30 (18%)
Relationship of Respondent	Mother	157 (94%)
	Father	8 (4.8%)
	Other	2 (1.2%)
Co-morbid medical/developmental condition	Yes	69 (41.3%)
	No	98 (58.7%)
Sensory Problem	Yes	13 (7.8%)
	No	154 (92.2%)
Medication	Yes	75 (44.9%)
	No	92 (55.1%)
Group Category	LD alone	31 (18.6%)
	LD plus ASD	55 (32.9%)
	ASD	81 (48.5%)

The co-morbid medical/developmental conditions and medications were examined to establish if the sample may be biased in any way due to the over inclusion of a particular condition or medication. Tables 3.2. and 3.3. below report the 5 most common conditions and medications:

Table 3.2. Most common medical/developmental conditions reported by the participants

Medical/developmental condition	**Number of participants (%)**
Asthma	18 (10.7%)
ADHD	16 (9.5%)
Epilepsy / seizures	10 (5.9%)
Down Syndrome	5 (3.0%)
Cerebal Palsy	4 (2.4%)

Table 3.3. Most common medications reported by the participants

Medication	**Number of participants (%)**
Melatonin	23 (13.7%)
Inhaler	18 (10.7%)
Respiridone	9 (5.4%)
Methylphenidate	7 (4.2%)
Cetirizine	5 (3.0%)

Specific medical/developmental conditions and medications were not included in the analysis as these were not specified in the hypotheses. Additionally, there were limited numbers for each individual medical/developmental condition or medication, which would make statistical analysis problematic. Medical/developmental condition and medication were therefore included as a dichotomous 'yes/no' variable. There was very limited information on the specific IQ scores of the sample. Therefore, level of IQ cannot be reported as a sample characteristic.

3.2. Exploratory Data Analysis

3.2.1. Normality

The data were examined to check for normality of distribution. Tests of skewness and kurtosis (as recommended by Field, 2000) were performed for age, and total scores of the CHSQ, SCAS-P and ABC-C. A z score more than +/- 1.96 is considered problematic (Field, 2000).

The sample was found to be normally distributed for age, and the total score of the CSHQ. The total scores for the SCAS-P and ABC-C were positively skewed and transformed successfully using the square-root transformation (Tabachnick and Fidell, 2007). This information is displayed in Appendix IX.

3.2.2. Outliers

The data were examined for the presence of outliers. Univariate outliers were identified by examining box plots and stem-and-leaf diagrams. Four outliers were identified between the three measures, but these were not identified as 'extreme' outliers (i.e. more than 3 standard deviations from the mean, Kinnear and Gray, 2004). The diagrams and box plots are displayed in Appendix X. Analysis was carried out with and without outliers for each measure. This study aimed to capture a realistic clinical sample, therefore analysis with the outliers has been reported in this chapter. However, if removing the outliers changed the outcome of the analysis, this has been reported.

An exploratory regression (using participant id number as a dummy outcome variable) was carried out to identify any multivariate outliers. If the standard residual score is more or less than +/- 3, then multivariate outliers are identified. No multivariate outliers were identified using this criteria (Tabachnick and Fidell, 2007).

3.2.3. Reliability of the Measures

Cronbach's alpha co-efficients were examined for the CSHQ, SCAS-P, and the ABC-C. In order to be found reliable and show internal consistency, the alpha co-efficient must be greater than 0.70, (Kinnear and Gray, 2004). The CSHQ, SCAS-P and ABC-C all met this criteria (0.759, 0.798 and 0.797 respectively).

3.3. Descriptive Statistics

The total scores for CSHQ, SCAS-P, and ABC-C were examined. Means and standard deviations can be found in Appendix XI.

Owens et al. (2000) report that children are identified as having sleep problems if the total score is above 41. There are no norms or cut off points available for the subscales. The mean total score for the CSHQ is 51.57 indicating that, overall, the sample can be identified as having sleep problems. When examining cases individually, 129 (77.2%) scored above the cut off score for sleep problems and 38 (22.8%) did not.

The SCAS-P has norms for males and females, which are divided into age categories. These provide a cut-off score for each subscale and for the total score (Nauta et al., 2004). Cases were examined individually, and the proportion of the sample above and below the cut-off scores are displayed in Table 3.4. below:

Table 3.4. Number of participants above and below clinical cut-off for the subscales and total scores of the SCAS-P

Scale	**N**	**Number (%) Above Clinical Cut Off**	**Number (%) Below Clinical Cut Off**
Sub Scale 1: Separation Anxiety	167	56 (33.5%)	111 (66.5%)
Sub Scale 2: Social Phobia	167	55 (32.9%)	112 (67.1%)
Sub Scale 3: Generalised Anxiety	167	46 (27.5%)	121 (72.5%)
Sub Scale 4: Panic/Agoraphobia	167	94 (55.1%)	75 (44.9%)
Sub Scale 5: Physical Injury Fears	167	82 (49.1%)	85 (50.9%)
Sub Scale 6: Obsessive Compulsive Disorder	167	110 (65.9%)	57 (34.1%)
Total Score	**167**	**76 (45.5%)**	**91 (54.5%)**

The ABC-C does not have specific norms for parental report, therefore Aman and Singh (1994) recommend using the normative data for Teacher Report. This is divided into age categories and gender. Aman and Singh suggest that scores falling above the 85th percentile should be considered behaviour of a clinically significant level (i.e. CB). Normative data is not provided for the total score. Cases were

examined individually and the proportion of the sample above and below the 85th percentile are displayed in Table 3.5. below:

Table 3.5. Number of participants above and below the 85th percentile for the subscales of the ABC-C

Scale	**N**	**Number (%) Above the 85th Percentile**	**Number (%) Below the 85th Percentile**
Sub Scale 1: Irritability, Agitation and Crying	167	58 (34.7%)	109 (65.3%)
Sub Scale 2: Lethargy and Social Withdrawal	167	59 (35.3%)	108 (64.7%)
Sub Scale 3: Stereotypic Behaviour	167	76 (45.5%)	91 (54.5%)
Sub Scale 4: Hyperactivity and Noncompliance	167	47 (28.1%)	120 (71.9%)
Sub Scale 5: Inappropriate Speech	167	109 (65.3%)	58 (34.7%)

3.4. Main Results

3.4.1. Hypothesis 1

Sleep problems, anxiety and CB will be significantly higher in the LD+ASD group, compared to the LD alone and ASD alone groups.

Hypothesis 1 was tested using One-Way ANOVA.[2] It should be noted that the analysis for hypothesis one did not achieve statistical levels of power due to the small number of participants in the LD group, indicating that these results should be interpreted with caution. The means and standard deviations for the three groups (LD, LD+ASD, ASD) for the CSHQ, SCAS-P and ABC-C are displayed in Table 3.6. below:

Table 3.6.: Means and standard deviations of the CSHQ, SCAS-P and ABC-C for each group

Measure	**Group**	**N**	**Mean**	**St Dev**
CSHQ	LD	31	51.19	10.71
	LD+ASD	55	52.89	9.89
	ASD	81	50.81	11.17
SCAS-P	LD	31	4.97	1.39
	LD+ASD	55	5.33	1.82
	ASD	81	5.49	1.69
ABC-C	LD	31	7.16	2.31
	LD+ASD	55	7.76	2.65
	ASD	81	6.83	2.04

No difference was found between the three groups (LD, LD+ASD, ASD) on total scores of the CSHQ and ABC-C ($F_{2,164} = 0.642$, $p = 0.527$), ($F_{2,164} = 2.648$, $p =$

[2] The effect size produced by SPSS is consistent with the eta squared formula ($\eta 2$ = SS between/SS total) reported by Clark-Carter (1997). Based on the calculation of $\eta 2$, Clark-Carter provides transformations of Cohen's original cut off values for identifying small, medium and large effect sizes. Accordingly, $\eta 2$ of 0.01 is a small effect size, $\eta 2$ of 0.059 is a medium effect size and $\eta 2$ of 0.138 is a large effect size. Additionally, SPSS produces a value for power in an ANOVA.

0.074) respectively. The analysis revealed a significant effect for the SCAS-P ($F_{2,164} = 3.062$, $p < 0.05$), indicating differences in the variance of the scores of the SCAS-P between the three groups. A small to medium effect size (0.037) and power of 0.585 were obtained. From examination of the means it appears that the ASD group showed the highest scores, followed by the LD+ASD group, followed by the LD group. However, Bonferroni Post Hoc tests revealed no significant differences between any combination of the three groups, suggesting that following adjustment for multiple comparisons, there are no significant differences in the scores between the groups.

When the same analysis was run with the outliers removed, different results were found. The means and standard deviations for the three groups (LD, LD+ASD, ASD) for the CSHQ, SCAS-P and ABC-C are displayed in Table 3.7. below:

Table 3.7. Means and standard deviations of the CSHQ, SCAS-P and ABC-C for each group, following the removal of outliers

Measure	**Group**	**N**	**Mean**	**St Dev**
CSHQ	LD	31	51.19	10.71
	LD+ASD	55	52.89	9.89
	ASD	80	51.40	10.59
SCAS-P	LD	31	4.97	1.39
	LD+ASD	55	5.33	1.82
	ASD	78	5.63	1.50
ABC-C	LD	31	7.16	2.32
	LD+ASD	54	7.90	2.45
	ASD	81	6.83	2.04

No difference was found in the scores between the groups for the CSHQ and SCAS-P respectively ($F\ 2,163 = 0.942$, $p = 0.392$); ($F\ 2,161 = 2.026$, $p = 0.135$). However, when the outliers were removed on the ABC-C scale, a significant effect of group category was found for the ABC-C ($F\ 2,163 = 3.752$, $p < 0.05$), indicating variance of the scores of the ABC-C between the three groups. A small to medium effect size (0.044) and power of 0.679 were obtained. The Bonferroni Post Hoc test revealed a significant difference between the LD+ASD and ASD groups ($p < 0.05$), suggesting that the LD+ASD group scored significantly higher on the ABC-C total score (i.e. significantly higher levels of CB) than the ASD group.

3.4.2. Exploration of Relationships Between the Factors

In order to explore the subsequent hypotheses, it was necessary to examine the potential impact of the demographic variables on the total scores of the CSHQ, SCAS-P and ABC-C. This would indicate if any of these variables should be considered in the further analysis exploring the relationships between factors.

One-Way ANOVAs were carried out on all of the available demographic information. Age, gender, relationship of respondent, sensory condition, and co-morbid medical/developmental condition were found to be not significant for any of the three measures. This information is displayed in Appendix XII.

Whether a child was on medication or not revealed a significant effect for all three measures showing that children on medication scored significantly higher on all three measures compared to the children not on medication. CSHQ: ($F\ 1,165 = 14.059$, $p<0.001$). This indicates a medium to large effect size (0.079) and power of 0.961. SCAS-P: ($F\ 1, 165 = 4.835$, $p<0.05$). This indicates a small to medium effect size (0.028) and power of 0.589. ABC-C: ($F\ 1,165 = 13.108$, $p<0.001$). This indicates a medium to large effect size (0.074) and power of 0.949.

The results of this analysis, plus the previous findings reported in Hypothesis 1, suggest that medication and group category should be taken into account in the subsequent analysis.

3.4.3. Hypothesis 2

There will be a significant positive correlation between sleep problems and anxiety in children with LD and/or ASD.

Hypothesis 2 was tested using a bivariate two-tailed Pearson's Product Moment correlation to test the association between the total scores of the CSHQ and SCAS-P for the full sample.[3] A significant positive correlation was found ($r=0.56$; $n=167$; $p<0.001$) indicating a significant association between sleep and anxiety in children with LD and/or ASD. In this correlation, a large effect size (0.56) and power of 0.995 were identified (Cohen, 1992). This relationship is demonstrated in Figure 3.1. below:

[3] In Hypotheses 2, 3 and 4 the effect size is the r value, as recommended by Clark-Carter (1997) and Cohen (1992). Accordingly, an r of 0.10 is a small effect size, an r of 0.30 is a medium effect size, and an r of 0.50 is a large effect size. The power was identified from power tables produced by Clark-Carter, (1997).

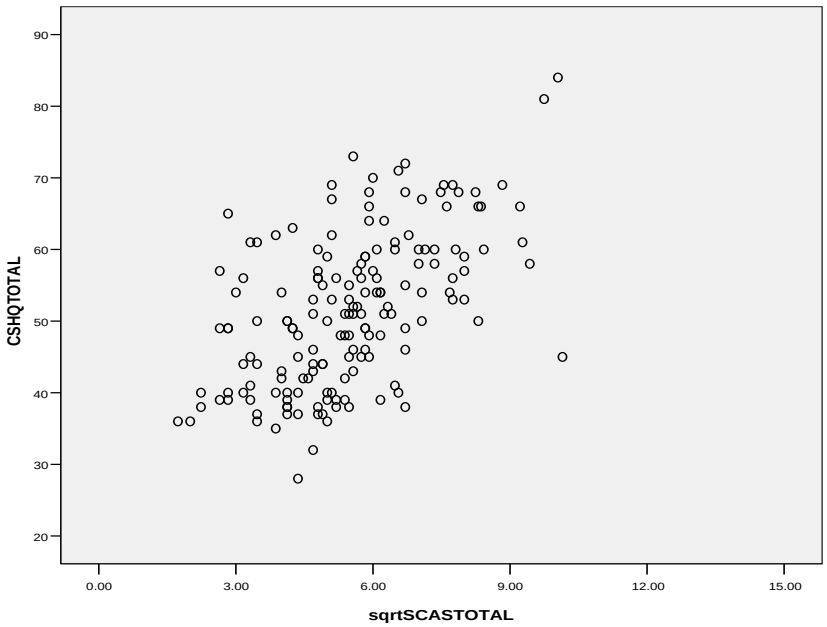

Figure 3.1. Scatter plot showing the association between total scores of the CSHQ and SCAS-P

In the previous One-Way ANOVA, medication and group category were found to impact on one or both of the CSHQ and the SCAS-P total scores. Partial correlations were therefore carried out to examine if the association between the CSHQ and the SCAS-P was still present after controlling for the presence of medication and group membership respectively. A significant positive correlation was still found between the CSHQ and SCAS-P after factoring out medication ($r=0.54$; $p<0.001$), and after factoring out group category ($r=0.56$; $p<0.001$).

3.4.3. Hypothesis 3

There will be a significant positive correlation between sleep problems and CB in children with LD and/or ASD.

Hypothesis 3 was tested using a bivariate two-tailed Pearson's Product Moment correlation to test the association between the total scores of the CSHQ and the ABC-C for the full sample. A significant positive correlation was found ($r=0.61$; $n=167$; $p<0.001$) indicating a significant association between sleep problems and CB in children with LD and/or ASD. In this correlation, a large effect size (0.61) and power of 0.995 were identified (Cohen, 1992). This relationship is shown in Figure 3.2 below:

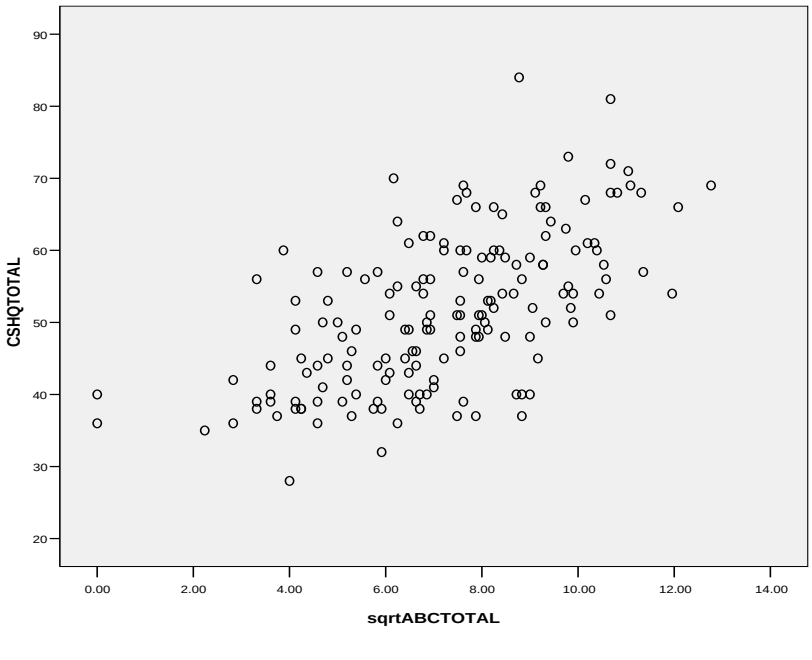

Figure 3.2. Scatter plot showing the association between total scores of the CSHQ and ABC-C

In the interest of completeness, a correlations were carried out between the individual subscales of the ABC-C and the total score of the CSHQ. This is displayed in Appendix XIII. A significant positive correlation was found between the total score of the CSHQ and each of the ABC-C subscales.

In the previous One-Way ANOVA, medication was found to impact on both of the CSHQ and the ABC-C total scores. In addition, when outliers were removed, group category impacted on ABC-C total scores. Partial correlations were therefore carried out to ascertain whether the association between the CSHQ and the ABC-C would still be present after controlling for the presence of medication and group category. A significant positive correlation was found between the CSHQ and ABC-C after factoring out medication ($r=0.58$; $p<0.001$) and after factoring out group category ($r=0.61$; $p<0.001$).

3.4.4. Hypothesis 4

There will be a significant positive correlation between anxiety and CB in children with LD and/or ASD.

Hypothesis 4 was tested using a bivariate two-tailed Pearson's Product Moment correlation to test the association between the total scores of the SCAS-P and the ABC-C for the full sample. A significant positive correlation was found, ($r=0.49$; $n=167$; $p<0.001$), indicating a significant association between sleep problems and CB in children with LD and/or ASD. In this correlation, a medium to large effect size (0.49) and power of 0.995 were identified (Cohen, 1992). This relationship is shown in Figure 3.3. below:

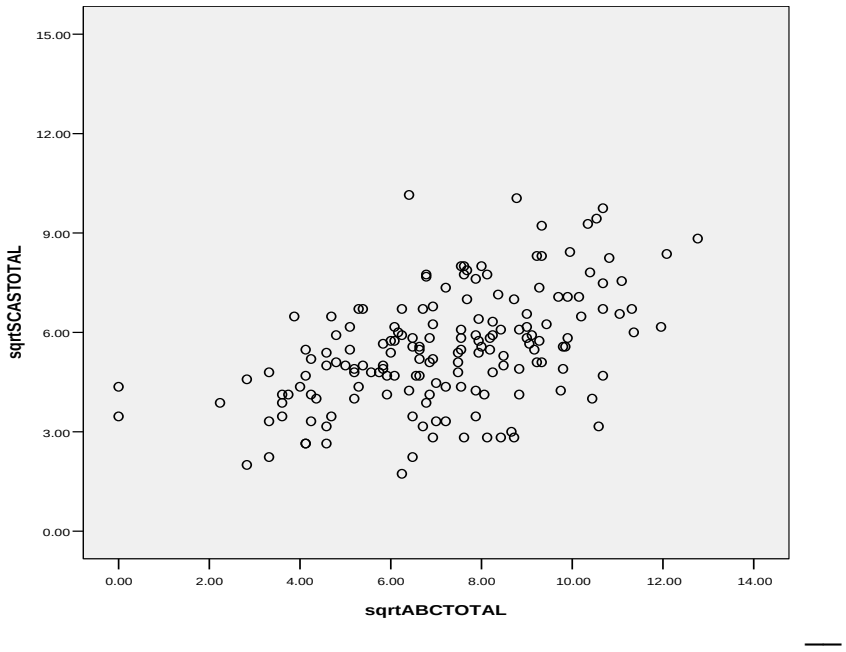

Figure 3.3. Scatter plot showing the association between total scores of the SCAS-P and ABC-C

Again, correlations were carried out between the individual subscales of the ABC-C and the total score of the SCAS-P. This is displayed in Appendix XIV. A significant positive correlation was found between the total score of the SCAS-P and each of the ABC-C subscales.

In the previous One-Way ANOVA, medication and group category were found to impact on one or both of the SCAS-P and the ABC-C total scores. Partial correlations were conducted to determine if the association between the SCAS-P and the ABC-C was still present after controlling for the presence of medication and group membership respectively. A significant positive correlation was found between the SCAS-P and the ABC-C after factoring out medication ($r=0.47$; $p<0.001$), and after factoring out group category ($r=0.53$; $p<0.001$).

3.4.5. Hypothesis 5

Sleep problems and anxiety will account for a significant amount of the variance in relation to challenging behaviour in children with LD and/or ASD.

Hierarchical multiple regression was carried out to explore which of the variables predicted the observed variance in the ABC-C total scores. In a hierarchical multiple regression the order in which the predictor variables are chosen to be entered into the model is based on past research and previous correlation analysis conducted with a study (Clark-Carter, 1997). Medication was found to impact on the total scores of the ABC-C and was entered into the regression model first. Group category was also found to impact on the total scores of the ABC-C. However, entering group category into the regression model was problematic. It was unclear if the groups were in fact discrete due to the overlapping symptoms of the LD+ASD group with the LD alone group and the ASD alone group. Additionally, group category did not correlate with the CSHQ and would therefore violate the assumption of linearity. This is displayed in Appendix XV. Therefore, Group category was not included in the regression model. Following medication, CSHQ was entered as this had a stronger correlation with the ABC-C than the SCAS-P, as recommended by Clark-Carter (1997). Finally, the SCAS-P was entered into the model. Previous research has found mixed results regarding the impact of age and co-morbid medical/developmental condition on challenging behaviour. As age and co-morbid medical/developmental condition did not impact on any of the measures in the previous analysis in this study, it was decided that these variables would not be entered into the regression.

Analysis revealed that the assumptions of the multiple regression were met. Previous correlations between the factors showed linearity and no multicollinearity was found. The Durbin-Watson statistic was found to be very close to 2, and therefore within appropriate parameters. Collinearity was shown to be appropriate through the variance inflation factor (VIF) and tolerance levels. Plots and histograms were reviewed for homoscedasticity and linearity, and no obvious problems were evident. This is displayed in Appendix XVI. The Cook's distance statistic was checked to identify any outliers, indicating a single case which could be influential on the overall model. Cook's distance was found to be within acceptable limits (within +/- 1, Tabachnick and Fidell, 2007). Mahalanobis distance was checked and within recommended parameters, indicating no multivariate outliers. The results of the hierarchical regression are reported in Table 3.8. below:

Table 3.8.: Results of the Regression Model for Predicting CB

	Model Summary			**ANOVA**		**Coefficients**		
Variable	**R2**	**Adjusted R**	**Sig value**	**F**	**Sig value**	**Std Beta**	**T Statistic**	**Sig value**
Medication	0.074	0.068	0.0001	13.108	0.0001	0.105	1.684	0.094
CSHQ	0.388	0.381	0.0001	52.020	0.0001	0.466	6.317	0.0001
SCAS-P	0.419	0.409	0.004	39.230	0.0001	0.213	2.956	0.004

The summary of the model indicates how much variance can be predicted in the outcome measure (Field, 2000; Tabachnick and Fidell, 2007), in this case CB.[4] The results suggest that medication accounted for 7.4% of the variance (R2 = 0.074), which was found to be statistically significant ($p<0.001$). This indicates a small to medium effect size (0.074) and power of 0.64. When CSHQ is added to the model, the variance accounted for rises to 38.8% (R2 = 0.388) which was also found to be statistically significant ($p < 0.001$). This indicates a large effect size (0.388) and power of 0.995. Finally, when SCAS-P was added to the model, the variance of CB explained rose to 41.9% (R2 = 0.419), which was also statistically significant ($p < 0.05$). This indicates a large effect size (0.419) and power of 0.995.

The ANOVA results from the regression analysis indicate if the model predicts the outcome (in this case CB) at a level significantly higher than chance (Field, 2000; Tabachnick and Fidell, 2007). In this case, medication, CSHQ, and SCAS-P were all found to be significant: ($F_{1,165} = 13.108$, $p < 0.001$); ($F_{2,164} = 52.020$, $p < 0.001$); ($F_{3,163} = 39.230$, $p < 0.001$) respectively. This suggests that overall, the model predicts CB at a level significantly higher than chance.

The t values and beta coefficients allow a measure of the extent to which each predictor contributes to the model, and to what degree each predictor impacts on the outcome, if the effects of all other predictors are held constant (Field, 2000;

[4] The effect sizes and power were calculated according to Clark-Carter (1997), where effect size = r2. Following the guidelines of Cohen (1988), Clark-Carter produced cut off values for small, medium and large effect sizes. Accordingly, r2 of 0.0196 is a small effect size, r2 of 0.13 is a medium effect size and r2 of 0.26 is a large effect size. Power was identified from the power tables produced by Clark-Carter (1997).

Tabachnick and Fidell, 2007). When the model encompasses all three factors, medication is no longer significant ($t = 1.684$, $p = 0.094$). CSHQ and SCAS-P are the stronger predictors of the ABC-C scores, ($t = 6.317$, $p < 0.001$); ($t = 2.956$, $p < 0.05$). Although SCAS-P scores significantly contribute to the model, the results suggest that CSHQ is the stronger predictor of ABC-C scores.

3.5. Summary of Results

The results indicated that a significant difference was found between the groups on the SCAS-P. However, post hoc tests did not indicate any differences when the groups were compared individually. When outliers were removed, significant differences were found between the groups on the ABC-C, indicating that the LD+ASD showed significantly more CB than the ASD alone group. Small to medium effect sizes were obtained for this analysis. Significant positive correlations were found between CSHQ and the SCAS-P, the CSHQ and the ABC-C, and between the SCAS-P and the ABC-C, indicating a positive association between these factors in the child LD/ASD population. Medium to large or large effect sizes were obtained for the correlational analysis. The regression analysis indicated that the proposed model of predictors (medication, sleep problems and anxiety) account for 41.9% of the variance of CB. When examining the model as a whole, sleep problems and anxiety appear to be significantly stronger predictors than medication, with sleep problems being found to contribute most to the model. The full model showed a large effect size.

Chapter 4: DISCUSSION

4.1. Introduction

This discussion will begin with a brief summary of the research and the main findings. The sample characteristics will then be reviewed and each hypothesis will be considered in more detail. Following this, the ethical and clinical implications will be discussed, with an emphasis on the possible implications for assessment, formulation and treatment. Finally, the strengths and weakness of the study and future avenues of research will be considered.

4.2. Summary of the Research

Previous research has indicated that sleep problems, anxiety and challenging behaviour (CB) are more common in children with LD and/or ASD than TD children (e.g. Baker et al., 2003; Emerson and Hatton, 2007; Richdale et al., 2000). Sleep and anxiety have been found to be associated in the TD population (e.g. Alfano et al., 2007). Whilst no studies in the LD/ASD population have examined this association specifically, some have produced results that suggest the possibility of this relationship (e.g. Allik et al., 2006). The association between sleep and challenging behaviour is fairly well established in the LD/ASD population (e.g. Wiggs and Stores, 1996). An association between psychopathology and CB has been noted in the adult LD/ASD population. Some studies have not been specific about the individual factors comprising 'psychopathology', but those that do identify anxiety specifically, suggest an association between anxiety and CB (e.g. Myrbakk and von Tetzchner, 2008). However, this relationship has not been sufficiently investigated

in the child LD/ASD population. Furthermore, whilst combinations of two of these three factors have been examined in various populations, the inter-relationships between the three factors have not yet been investigated together. The primary aim of this study was to examine the relationship between sleep problems and anxiety, sleep problems and CB, and anxiety and CB, in children with LD and/or ASD. Finally, the role of sleep problems and anxiety in predicting variance of CB was also investigated.

One hundred and sixty seven parental report measures of sleep problems, anxiety, and CB were gathered from four regions across Scotland. Significant positive correlations were found between sleep and anxiety, sleep and CB, and CB and anxiety. A hierarchical regression containing medication, sleep problems and anxiety was found to predict 41.9% of the variance in CB.

4.3. Discussion of the Research Findings

4.3.1. Sample Characteristics

The general demographics of the sample in this study were found to be consistent with the samples in other studies investigating similar factors. Questionnaires were returned for more males than females, which would be expected given the higher ratio of males with ASD in comparison to females. This uneven gender split has been noted in many other studies (e.g. Williams et al., 2004). Mothers were the most frequent respondents, which is common in parental report studies (Honomichl et al., 2002). Forty percent of the sample were found to have a co-morbid medical or

developmental diagnosis, and 44% were found to be taking medication. This would be expected given the high incidence of co-morbid medical conditions in the LD and ASD population (Courtman and Mumby, 2008). Only 7% of the sample indicated sensory problems, which is lower than would be expected from this population (Hodapp 1998).

Sleep problems were reported by 77.2% of the sample in this study, as indicated by the cut off score of the CSHQ. This is consistent with levels of sleep problems found in some previous studies (e.g. Polimeni et al. 2005), but higher than in others. For example Krakowiak et al., (2008) reported that between 46% and 53% of children with LD/ASD in their sample had sleep problems. These differences may have been due to the fact that the present study examined a clinical sample and a possible bias in return of questionnaire, which will be discussed further in section 4.5.5.

Anxiety was reported by 45.5% of the sample, as indicated by the cut off scores of the SCAS-P. This is consistent with levels of anxiety or emotional problems in children with LD/ASD reported in some previous studies (e.g. Einfeld and Tongue 1996a, 1996b), but less than in others . For example, Muris et al., (1998) reported that 81% of their sample met criteria for anxiety disorder. However, Muris et al. used an interview based study rather than a questionnaire method, which may have been more sensitive to anxiety symptoms. The level of anxiety reported in the current study was also higher than some previous studies. Emerson and Hatton (2007) noted only 11.4% of their sample showed anxiety. However, Emerson and Hatton did not use a clinical sample, which could explain the differences in anxiety levels reported.

Challenging behaviour was evident in 28%-65% of the sample, as indicated by subscale scores falling above the 85th percentile on the ABC-C. This is fairly consistent with findings by Lowe et al. (2007), who reported that 17% - 42% of the children in their study (in a total population study) showed serious CB. The level of CB found in the current study is higher than the 10-15% reported by Emerson et al. (2001). However, Emerson et al. used a total population sample, with adults included in this. An explanation of this difference could be that the current study used a sample of participants who were already known to clinical services, and may present with more CB.

4.3.2. Hypothesis 1

Sleep problems, anxiety and CB will be significantly higher in the LD+ASD group, compared to the LD alone and ASD alone groups.

There was mixed support for Hypothesis 1. Results indicated significant differences between the groups in levels of anxiety and CB, but not in relation to sleep problems. The findings will be discussed regarding each factor individually. Previously discussed literature surrounding the developmental, biological, psychological and social factors from which the hypothesis was derived will also be reviewed, and suggestions made as to why the observed findings were obtained. It should be remembered that due to low numbers in the LD alone group, the ANOVAs carried out did not meet levels of statistical power.

Sleep Problems

The results indicated that there were no differences between the groups on the measure of sleep problems (CSHQ). The descriptive statistics indicated that the sample as a whole suffered from sleep problems, but the analysis failed to find a difference in the level of sleep problems between the three groups. It was noted that past research into sleep problems has shown mixed results regarding the prevalence of sleep problems in LD and ASD groups. Whilst the results from this study do not support the hypothesis, the lack of difference between the groups in this study is consistent with some previous research (e.g. Williams et al., 2004).

The hypothesis in relation to sleep problems was based on previous research and developed following consideration of several factors. There are increased prevalence rates of sleep problems in children with syndromes, medical conditions and sensory problems that are associated with LD (e.g. Cotton and Richdale, 2005; Miano et al., 2008). It was thought that this, combined with the communication difficulties associated with both LD and ASD, and the specific need for routine in ASD, may increase sleep problems in the combined LD + ASD group. However, this was not found to be the case in this study. It is possible that the small number of children in the study with these syndromes and specific medical conditions associated with sleep may have resulted in less sleep problems in the children with LD than anticipated. Alternatively, as the sample was a clinical group, it is possible that the high prevalence of sleep problems overall meant that the questionnaire could not

distinguish between the three groups. However, as noted previously, this is an area that has found mixed results in the past.

Anxiety

The results indicated that there were significant differences between the groups in anxiety (SCAS-P). However, the Bonferroni post hoc test could not identify any differences when comparing between the groups in pairs. This post hoc test corrects the alpha level for multiple comparisons to avoid the chance of a Type 1 error. It seems that following this correction, the differences between groups were no longer significant. From examination of the means, it appears that the ASD group showed the highest scores, followed by the ASD+LD group, followed by the LD group. However, it is unclear which of these differences are significant. This result shows some consistency with previous findings. For example, Brereton et al. (2006) found differences in anxiety between groups of children with LD and ASD, with ASD showing significantly higher levels of anxiety than the LD group. Whilst the present study cannot identify where the differences between the specific groups lie, it does suggest that differences are apparent.

When the outliers were removed from the analysis, this finding was no longer significant. There were three cases identified as outliers on the SCAS-P. Examination of these cases revealed that they were all in the ASD group, and all scored particularly high on the measure. It seems that removing these outliers from the data set was sufficient to reduce the total SCAS-P scores in this group to render the difference between the groups not significant.

The hypothesis in relation to anxiety was based on previous research and was developed following consideration of several factors. The previously mentioned psychological theories of ASD (Theory of Mind Hypothesis, Weak Central Coherence Hypothesis, and Executive Dysfunction Hypothesis) suggest that individuals with ASD struggle to understand their own and others' minds, see the world in a fragmented fashion as opposed to a coherent whole, and have difficulty with attention, forward planning, and problem solving (Baron-Cohen, 1995; Happe and Frith, 1996; Pennington and Ozonoff, 1996). This could lead to difficulties in monitoring one's own internal state and individuals with ASD could see the world as frightening and unpredictable. Additionally, increased cortisol levels in children with ASD may lead them to be vulnerable to increased physiological arousal associated with anxiety (Corbett et al., 2006). Impaired cognitive function in individuals with LD leads to further difficulty in understanding stressful situations and also in problem solving to generate possible coping strategies (Bellini, 2006). It was thought that the co-existence of these two disorders may have a cumulative impact on the child in experiencing and coping with anxiety. As noted above, the analysis suggested that there was a difference between anxiety scores across the three groups. However, it was not possible to identify where these differences lay. It is possible that this may have been in part a result of the low numbers in the LD group, and greater participant numbers may have revealed significant differences in the follow up tests.

Challenging Behaviour

The initial ANOVA did not reveal a significant difference between the groups on scores of the ABC-C. One outlier was identified on the ABC-C. Examination of this case revealed that the participant was in the ASD+LD group, and rated CB as particularly low. When this case was removed from the data set, the analysis revealed a significant difference between groups on scores of the ABC-C. The Bonferroni post hoc test revealed that the LD+ASD group scored significantly higher than the ASD alone group. This finding is consistent with the findings of McClintock et al. (2003), who reported that a diagnosis of ASD was a risk factor for CB in individuals with a LD. The analysis did not, however, reveal a significant difference between the LD+ASD and LD alone group. It is possible that the low numbers in the LD alone group impacted on this finding. This finding should be interpreted with caution as it was identified following the removal of the outlier, and the ANOVA failed to meet statistical power in the LD alone group.

The hypothesis in relation to CB was based on previous research and was developed following consideration of several factors. Previous research has shown that various syndromes, medical conditions and medications have been associated with an increase in CB in children with LD/ASD (e.g. Schmitz, 2006). Communication difficulties are evident for both children with LD and ASD (e.g. Chiang, 2008), however, these may be more pronounced for children with both diagnoses due to impairment in verbal skills as a result of the LD. Additionally, poor executive functioning and deficits in theory of mind may result in difficulties in planning and

executing adaptive response to a demanding situation in children with ASD. Once a CB has been established, positive or negative reinforcement could serve to maintain the behaviour. As noted above, significantly higher levels of CB were found in the LD+ASD group when compared to the ASD alone group, suggesting that some of the above factors may be relevant.

In summary, there was mixed support for Hypothesis 1. The results suggest that the occurrence of sleep problems did not differ between groups. The results for anxiety and CB are less clear. It appears that differences between groups were either significant or not significant based on the removal of outliers from the sample. It seems that the impact of group category may impact on levels of anxiety and CB, with LD+ASD showing more CB than ASD alone. However, this should be interpreted with caution at this stage and further research is required to clarify these findings.

4.3.3. Hypothesis 2

Hypothesis 2 stated that there would be a significant positive correlation between sleep problems and anxiety in children with LD and/or ASD.

The current study revealed a significant positive correlation between sleep problems and anxiety, indicating that Hypothesis 2 can be accepted. This finding suggests that higher levels of sleep problems are associated with higher levels of anxiety in children with LD and/or ASD. Both group category (LD, LD+ASD, ASD) and medication were found to impact on anxiety scores, and medication was also found

to impact on sleep problems. However, further analysis revealed that the positive association between sleep problems and anxiety was still present and significant after factoring out the effect of group category and medication. This indicates that a relationship between sleep problems and anxiety is present, irrespective of group category and medication status. It should be noted, as has been highlighted in previous research, that a correlation suggests an association between factors, but does not inform the direction or causality of this relationship. This means that it cannot be stated that sleep problems cause anxiety, or that anxiety causes sleep problems, only that there is an association.

This hypothesis was based on previous research in the TD population and consideration of factors pertinent to the child LD/ASD population. Alfano et al. (2007) found that TD children with anxiety disorders also had high rates of sleep disorders. Additionally, Allik et al. (2006) suggested a link between sleep problems and anxiety in the LD/ASD population, but did not investigate this directly. The current study suggests that the associations found in the TD child population are also evident in the child LD/ASD population. This could be further explained by the interactions between developmental/biological, psychological and social factors discussed in section 1.6.1.4. In summary, anxiety is accompanied by physiological and cognitive arousal, which in turn could impair quality of sleep. This relationship could be bi-directional whereby lack of sleep leads to increased anxiety (Alfano et al., 2006). Additionally, if a child has sleep problems then these will impact on the parents' sleep. This could result in inconsistent and ineffective parenting. Parents may struggle to set boundaries and respond adaptively to the child, which may

disrupt attachment relationships and lead to further anxiety in the child (Van Ijzendoornet al., 1999).

4.3.4. Hypothesis 3

This hypothesis stated that there would be a significant positive correlation between sleep problems and CB in children with LD and/or ASD.

The current study revealed a significant positive correlation between sleep problems and CB, indicating that Hypothesis 3 can be accepted. This finding suggests that higher levels of sleep problems are associated with higher levels of CB. Both group category (LD, LD+ASD, ASD) and medication were found to impact on CB scores, and medication was also found to impact on sleep problems. However, further analysis revealed that the positive association between sleep problems and CB was still present and significant after factoring out the effect of group category and medication. This supports the suggestion that the relationship between sleep problems and CB is present, irrespective of group category and medication status. As stated previously, correlation implies only an association between factors, but not causality.

Support for this hypothesis was expected as a result of previous research in the child LD/ASD population. However, it was important to re-examine this finding in this study to ensure that the association was present and the current sample was consistent with previous research. Previous studies have reported an association between sleep and CB (e.g. Wiggs and Stores, 1996; Didden et al., 2002), in that

high levels of sleep problems were associated with high levels of CB. This could be further understood through the interactions between developmental/biological, psychological and social factors associated with sleep problems and CB discussed in section 1.6.2.3. In summary, sleep problems may be a form of CB, or they may contribute to their maintenance, or they could be associated with an underlying pathology of both LD and ASD, such as a communication deficit (Brylewski and Wiggs, 1999; Wiggs and Stores, 1996). Additionally, parents may reinforce CB, and lack of parental sleep could increase the difficulty in setting consistent behavioural boundaries.

4.3.5. Hypothesis 4

This hypothesis stated that there would be a significant positive correlation between anxiety and CB in children with LD and/or ASD.

The current study revealed a significant positive correlation between anxiety and CB, indicating that Hypothesis 4 can be accepted. This finding suggests that higher levels of anxiety are associated with higher levels of CB. Both group category and medication were found to impact on anxiety and CB. However, subsequent analysis revealed that the positive association between anxiety and CB was still present and significant after factoring out the effect of group category and medication. This indicates that the relationship between anxiety and CB is present, irrespective of group category and medication status. As stated previously, this correlation implies only an association between factors, but not causality.

This finding suggests that the previously discussed associations found between psychopathology and CB in the adult LD/ASD population are also evident in the child LD/ASD population. As noted earlier, the studies in the adult population often looked at 'psychopathology' or 'psychiatric disorder', and did not always identify anxiety specifically (e.g. Brereton et al., 2006). As discussed in section 1.6.3.3. this finding could be further explained by the interaction between developmental/biological, psychological and social factors pertinent to children with LD and/or ASD showing anxiety and CB. In summary, it may be that CB is an atypical presentation of psychiatric disorder, as in a behavioural equivalent (Hemmings et al., 2006). It could occur secondary to psychiatric disorder, or provide a setting event in which CB may occur, (Allen and Davis, 2007). Other factors such as communication and difficulty in understanding one's own state of mind are also likely to contribute to this finding. The present study does not specifically support one of these relationships, but shows that the relationship between anxiety and CB is present in children with and LD and/or ASD. Further information regarding the specific circumstances in which the CB occurred, and details about the form of the CB would be required to investigate this further.

4.3.6. Hypothesis 5

This hypothesis stated that sleep problems and anxiety will account for a significant amount of the variance in relation to CB in children with LD and/or ASD.

The current study revealed that sleep problems and anxiety accounted for a significant amount of the variance in relation to challenging behaviour. Therefore,

Hypothesis 5 can be accepted. A hierarchical regression model was chosen for this analysis as it allows predictors to be entered into the model in a specific order, informed by previous research and the results of the correlations within this study. Previous research had suggested that age, co-morbid medical/developmental or sensory condition may impact on amount of CB exhibited by children with LD and/or ASD. However, these were not included in the current study as analysis revealed that they did not impact on the ABC-C total scores. Medication was found to significantly impact on the total scores of the ABC-C, with children taking medication showing higher levels of CB than those not taking medication. This could be interpreted in two ways. Firstly, it is possible that the children on medication display more severe clinical problems, which is why they require medication. Secondly, due to the wide range of medical conditions and medications in the current sample, it could be that the side effect profile of the medications is resulting in increased difficulties in the areas of sleep, anxiety, or CB. The range of medications taken by the children in this study was too great to carry out further analysis on the impact or side effect profile of each medication, and lay outside of the scope of this research.

Medication was entered into the regression model as the first factor. By doing this, the variance accounted for by medication was controlled for before entering the hypothesised variables. Overall, medication, sleep problems and anxiety were found to account for 41.9% of the variance in CB. After sleep problems and anxiety had been entered into the model, medication was no longer found to be significant. This

suggests that the hypothesised variables (i.e. sleep problems and anxiety) are stronger and more significant predictors of CB than medication.

These results expand on previous research into the area of sleep problems, anxiety and CB. It has been noted several times in previous research (e.g. Brylewski and Wiggs, 1999) that there is limited information on the relationships between sleep problems, anxiety and CB, as many studies have been limited to correlational analysis only. The current study indicates that not only are these factors related in the child LD/ASD population, but that sleep and anxiety can predict a significant amount of the variance in CB. The previous review of the literature surrounding sleep problems, anxiety and CB in Chapter 1 did not indicate which factor (i.e. sleep or anxiety) would be most predictive of CB. The current study has shown that, whilst both sleep problems and anxiety are significant in predicting CB, sleep problems are the most significant predictor. This is an area of future research which will be discussed further in section 4.6.

4.3.7. Summary of Hypotheses

The results indicated that partial support was found for Hypothesis 1, but this must be interpreted with caution due to the low sample size in one group, and the differences found in the significance of results following the removal of outliers. It appears that the groups (LD, LD+ASD, ASD) differ on levels of anxiety, but it is not clear where the differences between groups lie. However, following the removal of outliers on the anxiety scale, the difference between the groups was no longer significant. When examining CB, no differences were found between groups in the

initial analysis. However, following the removal of one outlier, significant differences were found, with the LD+ASD group showing significantly more CB than the ASD alone group. This suggests that differences between the groups were dependant on the removal or inclusion of outliers, and further research is needed to clarify if these differences are a true effect and where exactly the groups differ. Hypotheses 2, 3 and 4 were upheld and showed significant positive correlations between sleep problems and anxiety, sleep problems and CB, and anxiety and CB, respectively. Hypothesis 5 was upheld as a model including medication, sleep problems and anxiety were found to predict a significant amount of the variance in CB.

4.4. Ethical and Clinical Implications

4.4.1. Clinical Assessment

The sample of children in this study were recruited from LD/ASD services and were not specifically identified as having sleep problems, anxiety or CB. It is possible that the returned sample was biased, with parents being more inclined to respond if they felt that the factors being examined were pertinent to them and their child, (this will be discussed further in section 4.5.5.). However, the fact remains that a high prevalence of sleep problems, anxiety and CB was evident in sample in this study. This suggests that high rates of sleep problems, anxiety and CB are present in children who present to clinical services, irrespective of the reason for referral. The associations found between the factors and the significant prediction of CB from sleep problems and anxiety suggest that if a child presents to clinical services with

one of these factors, the presence of other factors should be examined. It was noted previously that parents often believe that sleep problems are inherent as part of the LD or ASD diagnosis, and therefore may not highlight this during a clinical consultation (Honomichl et al., 2002; Polimeni et al., 2005). It is therefore important for clinicians to be aware of these associations to ensure that they can ask parents (or staff members working with the child) about a wide range of factors which may be impacting on the area of difficulty that the child has presented to services with. By not doing so could lead to gaps in the formulation and subsequent treatment, which would reduce the effectiveness of an intervention.

Dosen (2007) also highlights the importance of a multi-disciplinary team approach when assessing individuals with LD and other neurodevelopmental conditions. Dosen proposes that an integrative diagnosis must be given, which takes into account biological, developmental, social and psychological factors. By doing so, it is argued that the individual's overall needs will be met as a whole. This would encompass medication, meeting basic developmental needs, adapting surroundings according to needs and implementing specific psychological interventions when required. Clinicians should therefore consider a MDT approach and developmental, biological, psychological and social factors in assessment, formulation and intervention.

4.4.2. Treatment

The findings of this study could have important implications for treatment of sleep problems, anxiety and CB, and adaptations to current treatment strategies may be beneficial to staff and patients.

Treatment of CB has developed greatly over the last forty years, with a move from 'behaviour modification' to positive approaches including functional analysis and creating an enabling environment (Halliday and Mackrell, 1998). The British Psychological Society guidelines for CB indicate that treatment for CB should be both proactive (preventative) and reactive (when the behaviour is occurring), (British Psychological Society, 2004). This includes behavioural interventions, adapting the environment, general skills training, staff training, relaxation and functional communication training (Baker et al., 1998; Lindsay and Walker, 1998). Whilst positive outcomes for these interventions are reported (e.g. Braithwaite and Richdale, 2000), there is currently little evidence in the literature that other factors (such as sleep problems and anxiety) are assessed or targeted as part of a CB intervention. Additionally, there is evidence that the use of psychotropic drugs in the LD/ASD population is increasing (Kaperanovic and Simpson, 2006). However, in a recent review study, Matson and Neal (2009) reviewed studies examining medication use in CB, and reported that the benefit was minimal at best. The authors note that more controlled studies are needed and psychological intervention may have more long term benefits.

The results of the current study also have implications for interventions focusing on sleep problems or anxiety. At present, psychological/behavioural treatment studies tend to focus on the specific factor identified for treatment, whether sleep problems or anxiety, and do not assess or monitor additional factors, (e.g. Montgomery et al., 2004; O'Connell and Vannan, 2008; Sofronoff et al., 2005; Thackeray and Richdale,

2002; Willner, 2005). Additionally, sleep and anxiety are often treated by medication. Melatonin is often used to help sleep problems in children with LD/ASD (Bramble and Feehan; 2005; Keenan et al., 2007) and this has been found to be effective in the short term at least (Sajith and Clarke, 2007), although behavioural interventions are used more frequently (Williams et al., 2006). Similarly, McCarthy (2007) reviewed medication use for anxiety in children with LD/ASD and found that there is some evidence for a positive outcome in global functioning and a reduction in anxiety and repetitive behaviours. However, this author did note that many of the papers reviewed had poor methodology and sample size and more rigorous research is required in this area. It would appear that, from reviewing the literature, studies tend to focus on either a psychological/behavioural approach or medication approach, but rarely seem to combine these. The results of the current study would suggest that it is important to take into consideration a wide range of factors when planning interventions.

One treatment study was identified in the literature which incorporated both sleep and CB. Wiggs and Stores (1999) examined a behavioural intervention for sleep problems, and monitored the impact on daytime CB. This study did note an improvement in sleep following intervention, but the authors note that an observed reduction in CB was not related specifically to the sleep intervention. This was not the expected finding and the authors suggest that it is possible that the participants had such extreme behaviour that change was not easily detected, or that confounding variables such as medical conditions, genetic factors or family dynamics may have contributed to the CB to such an extent that the sleep intervention did not lessen

these behaviours. Additionally, they note that a small sample size and low statistical power may have contributed to this result.

With the exception of Wiggs and Store (1999), it seems clear that overall, treatment studies identify one factor (i.e. sleep problems, or anxiety or CB) and target treatment on this single factor, without taking into account the possible impact of other variables. Given the significant relationships between these variables found in the current study, it may be the case that assessing, monitoring, and potentially treating other factors associated with the target treatment variable would be beneficial. For example, if a child was referred for CB, and both sleep problems and anxiety were assessed and found to be problematic, these could be incorporated into the formulation and intervention. It could be that short term use of melatonin would allow sleep problems to decrease to a level where parents would be able to implement behavioural strategies that target the CB, and also allow healthier sleep patterns to develop. Additionally, if high levels of anxiety have been identified, strategies such as relaxation could be incorporated into the formulation and treatment plan. If all of these variables were monitored throughout treatment, this could potentially identify those that are most prominent for each individual child. Similarly, providing parents with an opportunity to access information about the potential factors that may be apparent in LD and/or ASD following diagnosis may empower parents and serve as a proactive strategy.

The current study found that children who were taking medication showed significantly higher levels of sleep problems, anxiety and CB than children who were

not taking medication. As noted previously, it is unclear if the children taking medication were doing so due to more severe problems, or if the side effect profile of certain medications were resulting in an increase in sleep problems, anxiety and CB. If a treatment programme was being designed for a child who was already taking medications, it would be prudent to review the side effect profile of these medications. Although sleep problems and anxiety were significant after the variance explained by medication was accounted for, medication was initially a significant predictor when entered on its own into the model. Therefore it would be important to consider the effect of medication within the formulation. This further emphasises the importance of MDT input for children with LD/ASD.

4.4.3. Summary of Ethical and Clinical Implications

Given the strong relationships found between sleep problems, anxiety, and CB in this study, it seems reasonable to suggest that if a child presents with one of these difficulties in clinic, then exploration of the surrounding factors may be valuable. Dosen (2007) further suggests that this should be carried out by a MDT, taking into account biological, developmental, psychological and social factors. Health professionals involved in the care of children with LD/ASD should be aware of potential relationships and how they may interact. Treatment studies to date have rarely taken into account symptoms that co-exist with the symptom targeted for treatment. This could result in a poorer treatment outcome for the individual. Families and carers of children with LD and/or ASD could also be given the opportunity for education and training to empower them and potentially intervene with difficulties before they reach clinical level.

4.5. Strengths and limitations of the study

4.5.1. Power and Effect Size

The current study had sufficient participant numbers to meet the requirements of statistical power for the correlational analysis and the regression analysis. This suggests that the effects found in these analyses were not susceptible to statistical error. Although there were sufficient participant numbers for the ANOVA within the groups as a whole, the earlier power calculation specified that 52 participants should be in each group. One group in this study had only 31 participants, which suggests that the analysis involving the ANOVA (Hypothesis 1) should be interpreted with caution. Small to medium effect sizes were found in hypothesis one, indicating that the results may be somewhat limited in terms of their clinical significance. However, the remaining hypotheses produced medium to large or large effect sizes, suggesting that the results produced are efficacious.

4.5.2. Sample

The sample in this study was collected from four regions across Scotland, and encompassed children attending NHS clinical services. Children with specific medical conditions and those taking medication were also included. It was thought that this would provide a realistic clinical sample of children attending services and reflect the types of referrals being made to clinical services. Furthermore, the wide geographical area included in this study suggests that the results could be generalised to different areas and services across Scotland.

4.5.3. Investigation of Factors

To the author's knowledge, this is the first study that has investigated sleep problems, anxiety and CB within one study and in the child LD/ASD population. Previous research has often commented on the limited information regarding the relationships between these factors. This study provides valuable information and several indicators for future research in this area and population. These will be discussed further in section 4.6.

4.5.4. Measures

Whilst the measures chosen for this study were considered the most appropriate, they are not without some limitations.

CSHQ

The CSHQ was chosen as it is has been found to be reliable and valid in the TD population. As noted previously, it has not been validated in the child LD/ASD population specifically, but has been used in this population in previous research, and was recommended as being suitable for use through personal correspondence with the author. Potentially the most reliable way of gathering information regarding sleep problems is through sleep actigraphy. This involves the individual wearing a watch-like device over a specified period of time, which measures different aspects of sleep and circadian rhythm. Sleep actigraphy devices tend to be used in studies with very small samples (e.g. Hering et al., 1999) due to the intensive nature of this method. Whilst this measure will give the most accurate measure of sleep, it was not

deemed appropriate for this study due to lack of resources and the desired large sample.

SCAS-P

The SCAS-P was chosen as the parental measure for anxiety. As noted previously, there is a lack of parental report measures examining anxiety specifically. Simonoff et al. (2008) used an interview based parental measure of psychopathology (the Child and Adolescent Psychiatric Assessment – Parent version) and reported high validity and reliability in a sample of children with ASD. Due to the geographical area, limited resources (i.e. no research team to conduct interviews) and desired sample size, this was not considered appropriate for use in the current study. Parental comments regarding the SCAS-P indicated that they were unsure of how to respond as they did not know what their child was thinking. Furthermore, on some of the partially complete data sets (which were not included in the sample), the parents did not complete the SCAS-P at all, commenting that it was unsuitable for their child due to deficits in communication or cognitive ability. It is therefore possible that the completed data sets represent children with LDs in the moderate to mild range as opposed to the severe range. The feedback from these parents further highlights the need for more parental measures of anxiety to be developed for use in the child LD/ASD population.

The ABC-C was used as the measure of CB in this study. Other commonly used measures of CB are the Child Behaviour Checklist (CBCL, Achenbach 1991) and the Developmental Behaviour Checklist (DBC, Einfeld and Tonge, 1994). The ABC-C

was chosen in preference to these measures as it is shorter (58 items as opposed to 118 and 96 items, respectively), which means that it would be less time consuming to complete. Additionally, the ABC-C focuses on behavioural factors specifically whereas the CBCL and DBC contain subscales measuring other elements of psychopathology. The current study was designed to include an individual measure of anxiety, as other studies have been criticised for using a single instrument to measure different factors (Patzold et al., 1998).

4.5.5. Questionnaire Design and Sample Bias

The participants in this study were parents or guardians of children and young people known to CAMHS, Community Child Health and Clinical Psychology services in four regions across Scotland. This indicates that the children and young people will already have some form of difficulty as they are already connected to services. The possibility of sample bias is highlighted as a problem area of questionnaire based studies by Oppenheim (1992). However, several procedures recommended by Oppenhiem were followed to try to ensure maximum return and an unbiased sample.

The participant information sheet included information regarding the background to the study and issues regarding confidentiality were explained. A stamped addressed envelope was included in the pack for ease of return. The participant information sheet also clearly stated that the study was gathering information about children who do, and do not, suffer from sleep problems, and anxiety and CB to try to ensure non-biased results. However, given that the sample was from a clinical population, this may have resulted in a biased sample, potentially inflating the severity of responses

on the questionnaires. Parents of children with difficulties in the area of sleep, anxiety and CB may also have been more motivated to return the questionnaires as they may have found them more relevant to their situation. Additionally, there is no information regarding the parents/guardians who did not return the questionnaires. Therefore no comparison can be made between the respondents and non-respondents. It could be the case that the respondents represented a specific subsection of the children who present to services, for example, more or less severe.

4.5.6. Parental Report

As noted previously, parental report was chosen as the means of gathering information as it was thought it would be impractical to gather the information from the children themselves, due to level of cognitive ability and potentially unreliable reporting. There is mixed evidence for the accuracy of parental report of the factors examined in this study. For example, Hering et al., (1999) reported that parents over estimate children's sleep problems. However, when using the CSHQ, Honomichl et al. (2002) report that parental report of children's sleep problems were reliable. It must be considered that the information returned may not be fully accurate.

4.5.7. Diagnoses of the Children

Potential participants were identified through on-site representatives in each region. Most of the on-site representatives use the procedures recommended by SIGN for diagnosis of ASD (e.g. MDT, 3DI, ADOS) during clinical practice. However, given the age range of the sample, and the length of time that the diagnostic procedures have been in place, it is not clear if all of the children in the current study will have

undergone this rigorous diagnostic procedure. This has implications for the division of groups in the study, as some of the ASD diagnoses may be less reliable than others. In addition, there was limited information regarding the specific IQ scores of the sample. It was therefore not possible to be certain of a clinical LD diagnosis, describe IQ in sample characteristics, or include level of LD in any of the analysis. Previous studies have shown mixed findings regarding the impact of IQ on sleep problems, anxiety and CB, therefore it is unclear if and how this information may have impacted on the findings of this study. However, given that the children identified to take part in this study were all known to the LD and ASD services in their respective regions, it is likely that the vast majority of the children will legitimately meet these diagnoses.

4.6. Future Research

This study was limited in its ability to explore the possible differential impact of neurodevelopmental disorder (i.e. LD, LD+ASD, ASD) on the relationships between sleep problems, anxiety, and CB. The linearity assumption had been violated therefore group category could not be included in the analysis, and there were insufficient numbers between the groups to run separate regression models for each group. It would be interesting to investigate the possible impact of a specific LD and/or ASD diagnosis on the relationships found in the current study, and explore the outcome of adding LD/ASD as a predictor to the model, or to explore the current model in different diagnostic groups.

When considering the implications for clinical practice discussed in sections 4.4.1. and 4.4.2., it would be of use to evaluate treatments for CB that incorporate other factors, such as sleep problems and anxiety. Equally, interventions for sleep problems and anxiety could assess and monitor the impact of associated factors. This would provide some insight into whether the predictive nature of sleep and anxiety translates to an actual clinical setting.

The results of this study suggested that 41.9% of CB was predicted by medication, sleep problems and anxiety. However, this leaves over half of the variance in CB unexplained. It would inform future intervention if information on other variables found to impact on CB were examined. For example, specific syndromes, parent stress, attachment style, and communication have all been found to be associated with CB in previous studies (Baker et al., 2003; Dykens, 2007; Janssen et al., 2002; McClintock et al., 2003; Murphy et al., 2005). Incorporating factors such as these would allow for the individual and cumulative impact of a wider range of variables to be established within a developmental, biological, psychological and social framework.

The current study examined sleep problems, anxiety and CB, but in a wide context. It could be that specific sub-types of anxiety and sleep problems could predict specific forms of CB. This could be investigated by examining the relationships between individual subscales of the measures. Furthermore, if a diagnostic category was included (e.g. LD or ASD) this could provide detailed information about specific difficulties within and between different conditions.

4.7. Summary and Conclusion

This study examined the relationships between sleep problems, anxiety and CB in a clinical sample of children with LD and/or ASD. A high prevalence of these factors has previously been found in the child LD/ASD population. However, the relationships between these factors has been an area of neglect as previous studies have focused on TD child or adult LD/ASD populations when examining relationships between factors. A questionnaire based study involving parental report was designed and five hypotheses were developed. The first hypothesis of the study stated that children with LD+ASD would show significantly more sleep problems, anxiety and CB than children with LD alone or ASD alone. The following hypotheses stated that significant positive correlations would be found between sleep problems and anxiety, sleep problems and CB, and anxiety and CB, respectively. The final hypothesis stated that sleep and anxiety would predict a significant amount of CB.

Results of the statistical analysis showed mixed support for the first hypothesis, and the remaining hypotheses were all upheld. Significant differences were found between scores in anxiety and CB between the LD alone, LD+ASD, and ASD alone groups, however, these results must be interpreted with caution due to low numbers in the LD alone group and lack of significance found in the post hoc test in the anxiety analysis. Significant positive correlations were found between sleep problems and anxiety, sleep problems and CB, and anxiety and CB. These

relationships remained when the effects of medication and group were partialled out. A hierarchical regression model was developed, incorporating medication, sleep problems and anxiety. The full model accounted for 41.9% of CB in the current study and showed a large effect size. The results can be related to previous findings in the literature.

The findings of the current study could have implications for assessment, formulation and treatment in clinical services. It appears from the literature that medical or psychological treatment for sleep problems, anxiety or CB tends to focus only on the target factor for treatment, without assessing or monitoring other factors. The current study suggests that it may be important for clinicians to have a full understanding of potential relationships between these factors and tailor assessment and treatment with this in mind.

The strengths of this study included the large sample size and focus on a realistic clinical population. However, results must be viewed in light of potential sample bias through postal survey and possible inaccuracy of information from parent report. As this study was the first to examine the relationships between sleep problems, anxiety and CB, the results have indicated several avenues of future research. For example, examining the regression model in different subgroups of neurodevelopmental condition, evaluating treatment studies incorporating all three factors and investigating what other factors could be incorporated into the regression model to further predict CB.

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List of Appendices

APPENDIX 1

Documentation of Ethical Approval

APPENDIX II

Letter of Invitation

Dear Parent / Guardian,

NHS ** are collaborating with NHS **** on a project looking at the relationships between sleep problems, anxiety and challenging behaviour. The Principle Investigator for this study is **name**, Trainee Clinical Psychologist, NHS ****. The onsite representative for NHS **** is **name**.**

As Principle Investigator, I am currently completing my final year of clinical psychology post graduate training at the University of Edinburgh. As part of my training I am carrying out a research project, and I am writing to invite you to take part in my study. It is hoped that findings from this study will help clinicians and researchers better understand the relationships between sleep, anxiety and challenging behaviour, and inform current practice. By way of background information, within this pack I have provided you with an information sheet, consent and demographic information form, three questionnaires, and a stamped addressed envelope. Before you decide whether or not to take part, it is important that you understand why this research is being carried out, and what will be required of you. Please read the information form carefully, and contact myself, or either of my supervisors, if you have any questions or concerns. Details can be found at the end of the information sheet. If you agree to take part, please complete the consent form and questionnaires, and return them to me in the envelope provided by **DATE**. Please note that your decision to take part or not, will not affect the current or future service that you receive from the NHS in any way.

Many thanks for reading this information,

Yours sincerely,

Name of trainee **Name of Onsite Representative**

APPENDIX III

Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Sleep, anxiety and challenging behaviour,
in children and young people with learning disabilities
and / or autism spectrum disorder

My name is ***** and I am a student of Edinburgh University, and an employee of NHS ****. I am required to undertake a project as part of my clinical psychology doctorate course and invite you to take part in the following study. However, before you decide to do so, I need to be sure that you understand firstly why I am doing it, and secondly what it would involve if you agreed. I am therefore providing you with the following information. Please read it carefully and be sure to contact myself or my supervisors (details at the end) with any questions you might have.

BACKGROUND TO THE PROJECT

This is a joint project between NHS ****, NHS ****, NHS **** and NHS ****.

What is the project about?

Previous research has found that children with learning disabilities (LD) and / or autism spectrum disorder (ASD) often have sleep problems, high levels of anxiety, and show challenging behaviour. These difficulties have been shown to impair the child's quality of life, and impact on other family members. It is therefore important to gain a better understanding of the relationship between these factors to help to inform future treatment options, and add to the research base in this area.

Why am I being asked to take part?

You are being asked to take part because you are the parent or guardian of a child or young person who is known to the LD service in your region and/or has a diagnosis of ASD. *I do not know if your child has any difficulties in sleep, anxiety, or challenging behaviour, as it is important to gather information about children who do, and do not, have problems in these areas*. I am asking several parents or guardians in the different regions outlined above to consider taking part.

Will taking part be of benefit to me, or others in the future?

If you decide to take part, you will be helping us to understand more about sleep problems, anxiety, and challenging behaviour in children and young people with a LD and/or ASD. It is hoped that this will help us to improve services for children with difficulties in these areas in the future. If you would like to receive feedback about the overall results of the study, then please indicate this on the consent form, and feedback will be sent to you on completion of the study.

WHAT DOES THE PROJECT INVOLVE?

What will I be asked to do?

This study will involve you completing four questionnaires. The first asks you for some brief information about your child, such as age and gender. The other questionnaires ask you about your child's sleep habits, anxiety, and behaviour. They should then be returned to me, along with the consent form, in the stamped addressed envelope provided. Each person participating in the study will be completing the same set of questionnaires.

How long will it take?

It is estimated that it will take approximately 40-50 minutes of your own time to complete the questionnaires.

Are there any discomforts or risks?

There are not thought to be any risks to you or your child from taking part in the study. It is not anticipated that the questionnaires will cause you any upset or concern. They are commonly used in clinical practice and research. However, if you were to become distressed in any way by the content, you can contact one of the numbers below, or alternatively, contact your GP or health professional involved with your child to arrange for further input.

What will happen to the information you collected from me?

The information collected from the questionnaires will be treated in the strictest confidence. On return to me, your questionnaires and consent forms will be marked with a code, and then separated, thereby making your answers anonymous. The data will be stored on a password protected computer, in a secure NHS building. All personal data will be destroyed on completion of the study.

WHAT ARE MY RIGHTS?

Do I have to take part?

You do not have to take part in this project, and even if you do, you are free to withdraw at any time, without having to give an explanation. Your decision to take part or not will have no effect at all on the treatment you receive now or in the future, or your relationship with any health professionals currently involved in your child's care.

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Contact details can be

found below. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from **** Hospital and Medical School. The **** Committee on Medical Research Ethics, which has responsibility for scrutinising all proposals for medical research on humans in ****, has examined the proposal and has raised no objections from the point of view of medical ethics.

Thank you for reading this information sheet and considering taking part.

Name and contact details of Principle Investigator

Name and contact details of Academic Supervisor

Name and contact details of Clinical Supervisor

APPENDIX IV

Consent Form

CONSENT FORM

**Sleep, anxiety, and challenging behaviour,
in children and young people with learning disabilities
and / or autism spectrum disorder**

	Please initial in the box provided
Have you read and understood the Participant Information Sheet?	☐
Have you received enough information about this study?	☐
If no, did you contact the research team and were your questions answered to your satisfaction?	☐
Do you understand that your participation is entirely voluntary?	☐
Do you understand that you are free to withdraw from the study:	
At any time?	☐
Without giving a reason?	☐
Without affecting your present or future care?	☐
Do you agree to take part in this study?	☐

Participant's signature……
Date……..

Participant's name in block
capitals……

I am the parent/guardian of…….. ……
DOB……..

Do you wish to be kept informed regarding the results of the study? Y / N

If ‘yes’, please enter your details below:

Name……..
Address……..
……
……
Post Code……

Thank you for agreeing to take part in this study. Your answers are confidential and your data will be anonymised.

APPENDIX V

Demographic Information Sheet

DEMOGRAPHIC INFORMATION

Please complete the following information:

Your relationship to the child (please circle):

Mother

Father

Other (please specify)_____

Child's Gender (please circle):

Male

Female

Child's Age (in years and months): _____

Does your child have any medical conditions? (please circle):

No

Yes (please specify)_____

Is your child prescribed any medications? (please circle):

No

Yes (please specify)_____

Does your child have any sensory conditions? (please circle):

No

Yes (please specify)_____

Does your child have a learning disability? (please circle):

No

Yes (please specify cause if known)_____

Does your child have an autism spectrum disorder? (please circle):

No

Yes (please specify if known)_____

Thank you for completing this questionnaire. All information will be kept strictly confidential.

APPENDIX VI

Child's Sleep Habits Questionnaire

Child's Sleep Habits Questionnaire (Pre-School and School Aged)

Judith A Owens, MD, MPH

The following are statements about your child's sleep habits and possible difficulties with sleep. Think about the past week in your child's life when answering these questions. If the last week was unusual for a specific reason (such as your child had an ear infection and did not sleep well, or the TV set was broken), chose the most typical week. Answer USUALLY if something occurs **5 or more times** in a week; answer SOMETIMES if it occurs **2-4 times** in a week; answer RARELY if something occurs **never or 1 time** during a week. Also, please indicate whether or not the sleep habit is a problem by circling "Yes", "No" or "Not Applicable (N/A)".

Bedtime

Write in child's bedtime:_____

	3 Usually (5-7)	**2 Sometimes (2-4)**	**1 Rarely (0-1)**	**Problem?**		
1) Child goes to bed at the same time each night	□	□	□	Yes	No	N/A
2) Child falls asleep within 20 minutes after going to bed	□	□	□	Yes	No	N/A
3) Child falls asleep in own bed	□	□	□	Yes	No	N/A
4) Child falls asleep in parent's or sibling's bed	□	□	□	Yes	No	N/A
5) Child needs parent in the room to fall asleep	□	□	□	Yes	No	N/A
6) Child struggles at bedtime (Cries and refuses to stay in bed etc)	□	□	□	Yes	No	N/A
7) Child is afraid of sleeping in	□	□	□	Yes	No	N/A

the dark						
8) Child is afraid of sleeping alone	□	□	□	Yes	No	N/A

Sleep Behaviour

Child's usual amount of sleep each day:_____hours and _____minutes (combining nighttime sleep and naps)

	3 Usually (5-7)	**2 Sometimes (2-4)**	**1 Rarely (0-1)**	**Problem?**		
9) Child sleeps too little	□	□	□	Yes	No	N/A
10) Child sleeps the right amount	□	□	□	Yes	No	N/A
11) Child sleeps about the same amount each day	□	□	□	Yes	No	N/A
12) Child wets the bed at night	□	□	□	Yes	No	N/A
13) Child talks during sleep	□	□	□	Yes	No	N/A
14) Child is restless and moves a lot during sleep	□	□	□	Yes	No	N/A
15) Child sleepwalks during the night	□	□	□	Yes	No	N/A
16) Child moves to someone else's bed during the night	□	□	□	Yes	No	N/A

(parent, brother, sister etc)

17) Child grinds teeth during sleep (your dentist may have told you this)	□	□	□	Yes	No	N/A
18) Child snores loudly	□	□	□	Yes	No	N/A
19) Child seems to stop breathing during sleep	□	□	□	Yes	No	N/A
20) Child snorts and/or gasps during sleep	□	□	□	Yes	No	N/A
21) Child has trouble sleeping away from home (visiting relatives, vacation)	□	□	□	Yes	No	N/A
22) Child awakens during night screaming, sweating, inconsolable	□	□	□	Yes	No	N/A
23) Child awakens alarmed by a frightening dream	□	□	□	Yes	No	N/A

Waking During the Night

	3	**2**	**1**			
	Usually	**Sometimes**	**Rarely**	**Problem?**		
	(5-7)	**(2-4)**	**(0-1)**			
24) Child awakens once during the night	□	□	□	Yes	No	N/A
25) Child awakens more than once during the night	□	□	□	Yes	No	N/A

Write the number of minutes a night waking usually lasts:_____

Morning Waking / Daytime Sleepiness

Write in the time of day child usually wakes in the morning:_____

	3	2	1			
	Usually	**Sometimes**	**Rarely**	**Problem?**		
	(5-7)	**(2-4)**	**(0-1)**			
26) Child wakes up be himself/herself	□	□	□	Yes	No	N/A
27) Child wakes up in a negative mood	□	□	□	Yes	No	N/A
28) Adults or siblings wake up child	□	□	□	Yes	No	N/A
29) Child has difficulty getting out of bed in the morning	□	□	□	Yes	No	N/A
30) Child takes a long time to become alert in the morning	□	□	□	Yes	No	N/A
31) Child seems tired	□	□	□	Yes	No	N/A

Child has appeared very sleepy or fallen asleep during the following:

	1	2	3
	Not sleepy	**Very sleepy**	**Falls asleep**
32) Watching TV	□	□	□
33) Riding in car	□	□	□

APPENDIX VII

Spence Children's Anxiety Scale – Parent Version

SPENCE CHILDREN'S ANXIETY SCALE – PARENT REPORT

Susan Spence, 1999; Nauta et al. 2004

BELOW IS A LIST OF ITEMS THAT DESCRIBE CHILDREN. FOR EACH ITEM PLEASE CIRCLE THE RESPONSE THAT BEST DESCRIBES YOUR CHILD. PLEASE ANSWER ALL ITEMS.

1.	My child worries about things	Never	Sometimes	Often	Always
2.	My child is scared of the dark	Never	Sometimes	Often	Always
3.	When my child has a problem, (s)he complains of having a funny feeling in his/her stomach	Never	Sometimes	Often	Always
4.	My child complains of feeling afraid	Never	Sometimes	Often	Always
5.	My child would feel afraid of being on his/her own at home	Never	Sometimes	Often	Always
6.	My child is scared when (s)he has to take a test	Never	Sometimes	Often	Always
7.	My child is afraid when (s)he has to use public toilets or bathrooms	Never	Sometimes	Often	Always
8.	My child worries about being away from us/me	Never	Sometimes	Often	Always
9.	My child worries that (s)he will make a fool of him/herself in front of people	Never	Sometimes	Often	Always
10.	My child feels afraid that (s)he will do badly at school	Never	Sometimes	Often	Always
11.	My child worries that something awful will happen to someone in our family	Never	Sometimes	Often	Always
12.	My child complains of suddenly feeling as if (s)he can't breathe when there is no reason for this	Never	Sometimes	Often	Always
13.	My child has to keep checking that (s)he has done things right (like the switch is off, the door is locked)	Never	Sometimes	Often	Always
14.	My child is scared if (s)he has to sleep on his/her own	Never	Sometimes	Often	Always
15.	My child has problems going to school in the mornings because (s)he feels nervous or afraid	Never	Sometimes	Often	Always
16.	My child is scared of dogs	Never	Sometimes	Often	Always
17.	My child can't seem to get bad or silly thoughts out of his/her head	Never	Sometimes	Often	Always

18.	When my child has a problem, s(he) complains of his/her heart beating really fast	Never	Sometimes	Often	Always
19.	My child suddenly starts to tremble or shake when there is no reason for this	Never	Sometimes	Often	Always
20.	My child worries that something bad will happen to him/her	Never	Sometimes	Often	Always
21.	My child is scared of going to the doctor or dentist	Never	Sometimes	Often	Always
22.	When my child has a problem, (s)he feels shaky	Never	Sometimes	Often	Always
23.	My child is scared of heights (eg. Being at the top of a cliff)	Never	Sometimes	Often	Always
24.	My child has to think special thoughts (like numbers or words) to stop bad things from happening	Never	Sometimes	Often	Always
25.	My child feels scared if (s)he has to travel in the car, or on a bus or train	Never	Sometimes	Often	Always
26.	My child worries what other people think of him/her	Never	Sometimes	Often	Always
27.	My child is afraid of being in crowded places (like shopping centres, the movies, buses, busy playgrounds)	Never	Sometimes	Often	Always
28.	All of a sudden, my child feels really scared for no reason at all	Never	Sometimes	Often	Always
29.	My child is scared of insects or spiders	Never	Sometimes	Often	Always
30.	My child complains of suddenly becoming dizzy or faint when there is no reason for this	Never	Sometimes	Often	Always
31.	My child feels afraid when (s)he has to talk in front of the class	Never	Sometimes	Often	Always
32.	My child complains of his/her heart suddenly starting to beat too quickly for no reason	Never	Sometimes	Often	Always
33.	My child worries that (s)he will suddenly get a scared feeling when there is nothing to be afraid of	Never	Sometimes	Often	Always
34.	My child is afraid of being in small closed spaces, like tunnels or small rooms	Never	Sometimes	Often	Always
35.	My child has to do some things over and over again (like washing his/her hands, cleaning, or putting things in a certain order)	Never	Sometimes	Often	Always

36.	My child gets bothered by bad or silly thoughts or pictures in his/her head	Never	Sometimes	Often	Always
37.	My child has to do certain things in just the right way to stop bad things from happening	Never	Sometimes	Often	Always
38.	My child would feel scared if (s)he had to stay away from home overnight	Never	Sometimes	Often	Always

Is there anything else that your chid is really afraid of? YES NO

If yes, please write down what it is, and fill out how often (s)he is afraid of that thing?

_____ Never Sometimes Often Always

_____ Never Sometimes Often Always

_____ Never Sometimes Often Always

_____ Never Sometimes Often Always

APPENDIX VIII

Aberrant Behaviour Checklist – Community

ABERRANT BEHAVIOUR CHECKLIST – COMMUNITY

Aman and Singh, 1994

INSTRUCTIONS

The ABC-Community rating scale is designed to be used with clients living in the community. **Please note that the term *client* is used throughout to refer to the person being rated. This may be a child of school age, an adolescent, or an adult**.

Please rate this client's behaviour for the last four weeks. For each item, decide whether the behaviour is a problem and circle the appropriate number:

0 = not at all a problem
1 = the behaviour is a problem but slight in degree
2 = the problem is moderately serious
3 = the problem is severe in degree

When judging the client's behaviour, please keep the following points in mind:

(a) Take relative *frequency* into account for each behaviour specified. For example if the client averages more temper outbursts than most of the clients you know or most others in his/her class, it is probably moderately serious (rated 2) or severe (rated 3) even if these occur only once or twice a week. Other behaviours, such as non-compliance, would probably have to occur more frequently to merit an extreme rating.

(b) If you have access to this information, consider the experiences of other care providers with this client. If the client has problems with others but not you, try to take the whole picture into account.

(c) Try to consider whether a given behaviour interferes with his/her *development*, *functioning*, or *relationships*. For example, body rocking or social withdrawal may not disrupt other children or adults, but it almost certainly hinders individual development or functioning.

*Do not spend too much time on each item – your first reaction is usually the right one. Please circle **one** response for each item.*

1.	Excessively active at home, school, work, or elsewhere	0	1	2	3
2.	Injures self on purpose	0	1	2	3
3.	Listless, sluggish, inactive	0	1	2	3
4.	Aggressive to other children or adults (verbally or physically)	0	1	2	3
5.	Seeks isolation from others	0	1	2	3
6.	Meaningless, recurring body movements	0	1	2	3
7.	Boisterous (inappropriately noisy or rough)	0	1	2	3

8.	Screams inappropriately	0	1	2	3
9.	Talks excessively	0	1	2	3
10.	Temper tantrums / outbursts	0	1	2	3

11.	Stereotyped behaviour, abnormal, repetitive movements	0	1	2	3
12.	Preoccupied, stares into space	0	1	2	3
13.	Impulsive (acts without thinking)	0	1	2	3
14.	Irritable and whiny	0	1	2	3
15.	Restless, unable to sit still	0	1	2	3
16.	Withdrawn, prefers solitary activities	0	1	2	3
17.	Odd, bizarre in behaviour	0	1	2	3
18.	Disobedient, difficult to control	0	1	2	3
19.	Yells at inappropriate times	0	1	2	3
20.	Fixed facial expression, lacks emotional responsiveness	0	1	2	3

21.	Disrupts others	0	1	2	3
22.	Repetitive speech	0	1	2	3
23.	Does nothing but sit and watch others	0	1	2	3
24.	Uncooperative	0	1	2	3
25.	Depressed mood	0	1	2	3
26.	Resists any form of physical contact	0	1	2	3
27.	Moves or rolls head back and forth repetitively	0	1	2	3
28.	Does not pay any attention to instructions	0	1	2	3
29.	Demands must be met immediately	0	1	2	3
30.	Isolates himself/herself from other children or adults	0	1	2	3

31.	Disrupts group activities	0	1	2	3
32.	Sits or stands in one position for a long time	0	1	2	3
33.	Talks to self loudly	0	1	2	3
34.	Cries over minor annoyances and hurts	0	1	2	3
35.	Repetitive hand, body, or head movements	0	1	2	3
36.	Mood changes quickly	0	1	2	3
37.	Unresponsive to structured activities (does not react)	0	1	2	3
38.	Does not stay in seat (eg during lesson or training, meals etc)	0	1	2	3
39.	Will not sit still for any length of time	0	1	2	3
40.	Is difficult to reach, contact, or get through to	0	1	2	3

41.	Cries and screams inappropriately	0	1	2	3
42.	Prefers to be alone	0	1	2	3
43.	Does not try to communicate by words or gestures	0	1	2	3
44.	Easily distractible	0	1	2	3
45.	Waves or shakes the extremities (ie hands) excessively	0	1	2	3
46.	Repeats a word or phrase over and over	0	1	2	3
47.	Stamps feet or bangs objects or slams doors	0	1	2	3
48.	Constantly runs or jumps around the room	0	1	2	3
49.	Rocks body back and forth repeatedly	0	1	2	3
50.	Deliberately hurts himself/herself	0	1	2	3

51.	Pays no attention when spoken to	0	1	2	3
52.	Does physical violence to self	0	1	2	3
53.	Inactive, never moves spontaneously	0	1	2	3

54.	Tends to be excessively active	0	1	2	3
55.	Responds negatively to affection	0	1	2	3
56.	Deliberately ignores directions	0	1	2	3
57.	Has temper tantrums if he/she does not get own way	0	1	2	3
58.	Shows few social reactions to others	0	1	2	3

APPENDIX IX

Skewness and Kurtosis Summaries

Skewness and kurtosis statistics for the total score of the Child Sleep Habits Questionnaire, Spence Children's Anxiety Scale – Parent Version and Aberrant Behaviour Checklist – Community.

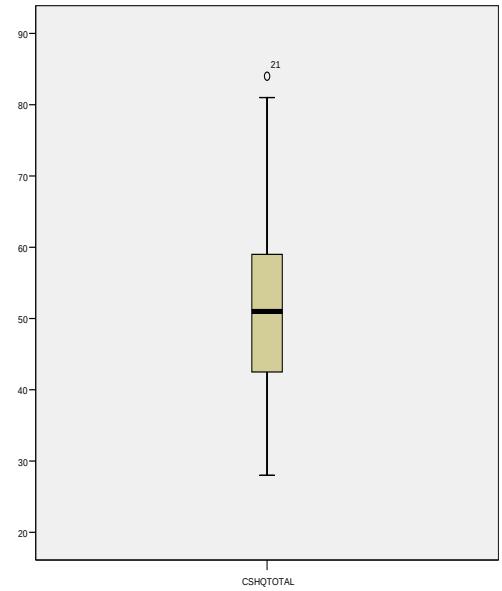
	Skewness		**Kurtosis**	
	Statistic	Std. Error	Statistic	Std. Error
CSQH Total	.329	.188	-.397	.374
SCAS-P Total	.332	.188	-.012	.374
ABC-C	-.251	.188	.049	.374

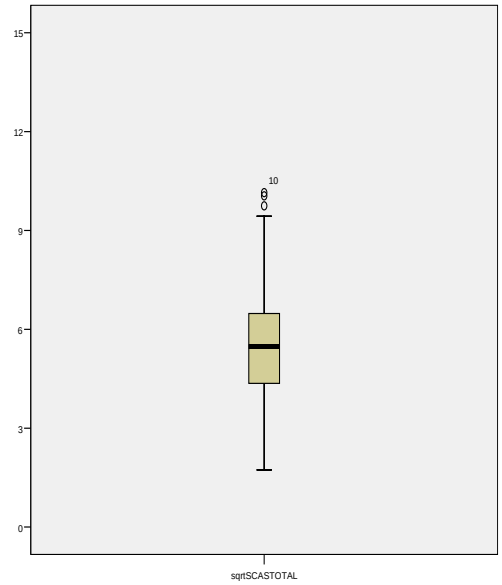
NB: SCAS-P and ABC-C skewness are kurtosis values are presented following the square root transformation.

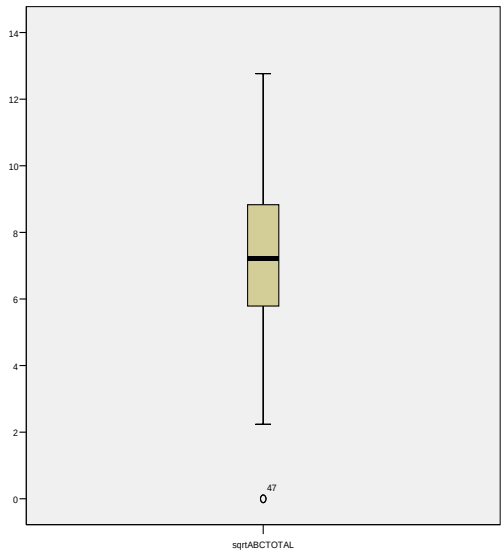
APPENDIX X

Box Plots Showing Outliers

Box Plots of outliters on total scores of the Child Sleep Habits Questionnaire, Spence Children's Anxiety Scale – Parent Version and Aberrant Behaviour Checklist – Community.







APPENDIX XI

Descriptive Statistics

Means and standard deviations for total scores of the Child's Sleep Habits Questionnaire, Spence Children's Anxiety Scale – Parent Version and Aberrant Behaviour Checklist – Community.

Measure	**N**	**Mean**	**Standard Deviation**
CSHQ	167	51.57	10.66
SCAS-P	167	33.04	20.10
ABC-C	167	57.25	33.10

NB: Non-transformed scores for the SCAS-P and ABC-C have been reported.

APPENDIX XII

Summary of Non Significant ANOVAs

Results of Non-Significant ANOVAs for Child Sleep Habits Questionnaire, Spence Children's Anxiety Scale – Parent Version and Aberrant Behaviour Checklist – Community.

	Gender		**Age**		**Relationship of Respondent**		**Co-morbid Medical/Developmental Condition**		**Sensory Condition**	
	F	**Sig**	**F**	**Sig**	**F**	**Sig**	**F**	**Sig**	**F**	**Sig**
CSHQ	0.000	.984	.824	.634	.292	.747	3.898	.051	.310	.578
SCAS-P	.166	.685	.812	.647	1.152	.319	.536	.465	.162	.688
ABC-C	.367	.546	1.023	.432	.204	.816	1.538	.217	.537	.465

APPENDIX XIII

Correlations between CSHQ and ABC-C subscales

Correlations between CSHQ and ABC-C subscales. N = 167 for each group.

	ABC-C 1	ABC-C 2	ABC-C 3	ABC-C 4	ABC-C 5
CSHQ					
rs	.571**	.556**	.398**	.498**	.336**
Sig	0.000	0.000	0.000	0.000	0.000

** Correlations are significant at the 0.01 level

NB: Non parametric correlations (Spearman's rho) were performed as the ABC-C subscale scores were not normally distributed, and did not meet criteria for skewness and kurtosis after transformation.

APPENDIX XIV

Correlations between SCAS-P and ABC-C subscales

Correlations between SCAS-P and ABC-C subscales. N = 167 for each group.

	ABC-C 1	ABC-C 2	ABC-C 3	ABC-C 4	ABC-C 5
SCAS-P					
rs	..467**	.478**	.327**	.317**	.451**
Sig	0.000	0.000	0.000	0.000	0.000

** Correlations are significant at the 0.01 level

NB: Non parametric correlations (Spearman's rho) were performed as the ABC-C subscale scores were not normally distributed, and did not meet criteria for skewness and kurtosis after transformation.

APPENDIX XV

Correlation Matrix

Correlation Matrix for medication, group category, CSHQ, SCAS-P and ABC-C. N=167 for each correlation

	Medication	**Group Category**	**CSHQ**	**SCAS-P**	**ABC-C**
Medication					
r	1	-.228**	.280**	.169*	.271**
Sig		.003	.000	.029	.000
Group Category					
r	-.228**	1	-.037	.189*	-.097
Sig	.003		.639	.014	.214
CSHQ					
r	.280**	-.037	1	.558**	.614**
Sig	.000	.639		.000	.000
SCAS-P					
r	.169*	.189*	.558**	1	.490**
Sig	.029	.014	.000		.000
ABC-C					
r	.271**	-.097	.614**	.490**	1
Sig	.000	.214	.000	.000	

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2 tailed).

NB: Correlations above 0.80 are considered problematic in terms of multicollinearity and singularity (Field, 2000). None of the above correlations were above 0.80.

APPENDIX XVI

Normality Probability Plot and Residual Scatterplot

Normality Probability Plot and residuals scatterplots for regression model.